PCOC

palliative care
outcomes collaboration

New South Wales

Patient Outcomes in Palliative Care

January to June 2023

August 2023

www.pcoc.org.au

What is PCOC?

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

Central to the program is a [framework and protocol for routine clinical assessment and response](). This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information. PCOC aims to drive improvement in patient outcomes through feedback to individual services and by facilitating service-to-service benchmarking.

The items in the PCOC data collection:
- provide clinicians with an approach to systematically assess individual patient experiences
- include routine Patient Reported Outcome Measures (PROMs) relating to symptom distress
- define a common clinical language to allow palliative care providers to communicate with each other
- facilitate the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement at service, state, territory and national levels.

The assessment framework incorporates five validated clinical assessment tools:
- Palliative Care Phase
- Palliative Care Problem Severity Score (PCPSS)
- Symptom Assessment Scale (SAS)
- Australia-modified Karnofsky Performance Status (AKPS) scale and
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

If you would like more information or have any queries about this report please contact the PCOC national office at pcoc@uow.edu.au or on (02) 4221 4411

Contents

Tables

Figures

Introduction

The Australian palliative care sector is a world leader in using routine clinical assessment information to guide patient-centred care and measure patient and family outcomes. Providers of palliative care are commended for their commitment to excellence in delivering evidence-based, patient-centred care by using the routine PCOC assessment framework and contributing patient data toward national outcome measurement and benchmarking. PCOC acknowledges the dedication and willingness of clinicians to improve the care of patients, their families and caregivers. The information collected is not just data - it represents the real-life outcomes of over 60,000 Australian patients each year.

While the focus of this report is on the most recent information relating to January to June 2023, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 36,772 patients, having 45,484 episodes of care and 98,152 palliative care phases from 209 services who provide palliative care in hospital or in the person's home.

The New South Wales figures in this report are based on information submitted by the services listed in Table 1 on the following page. A full list of the services included in the national figures can be found at www.pcoc.org.au.

Please use the following key when interpreting the tables:	
-	The item is not applicable.
u	The item was unavailable.
s	The item was suppressed due to insufficient data.

Table 1   List of NSW Services included in this report

Service name	Setting of care
Bellinger River District Hospital	Inpatient
Blacktown Hospital	Inpatient
Broken Hill Health Service	Inpatient and community
Broken Hill Health Service Consult	Inpatient
Buronga Specialist Palliative Care Service	Community
Calvary Health Care Kogarah	Inpatient and community
Calvary Health CareRiverina – Mary Potter PCU	Inpatient
Calvary Mater Newcastle	Inpatient
Central Coast Palliative Care Unit – Gosford Consult	Inpatient
Coffs Harbour Palliative Care Service	Community
Concord Centre for Palliative Care	Inpatient
Cowra Health Service	Inpatient
David Berry Hospital	Inpatient
Gosford Hospital	Inpatient
HammondCare – Braeside Hospital	Inpatient
HammondCare – Greenwich Hospital	Inpatient and community
HammondCare – Neringah Hospital	Inpatient and community
HammondCare Community Northern Beaches	Community
HammondCare Community Residential Aged Care Inreach	Community
Hastings Macleay Community Palliative Care Service	Community
Hornsby Hospital Palliative Care Consult Service	Inpatient
Illawarra Shoalhaven Community Service	Community
John Hunter Hospital	Inpatient
Liverpool Hospital	Inpatient
Macarthur Palliative Care Service Camden Hospital	Inpatient
Macksville Community Palliative Care Service	Community
Maitland Dungog Community Palliative Care Service	Community
Manning Rural Referral Hospital	Inpatient
Mona Vale Palliative Care Unit	Inpatient
Mudgee Health Service	Inpatient
Nepean Hospital	Inpatient

Service name	Setting of care
Northern Beaches Hospital Palliative Care Consult	Inpatient
Port Kembla Hospital	Inpatient
RPA Virtual Sydney District Nursing – Canterbury	Community
RPA Virtual Sydney District Nursing – Concord	Community
RPA Virtual Sydney District Nursing – Croydon	Community
RPA Virtual Sydney District Nursing – Marrickville	Community
RPA Virtual Sydney District Nursing – Redfern	Community
Royal North Shore Hospital Palliative Care Consult Service	Inpatient and community
Royal Prince Alfred Hospital	Inpatient
Ryde Hospital Palliative Care Consult Service	Inpatient and community
Silver Chain – Western Sydney LHD	Community
St John of God – Hawkesbury District Health Service	Community
St Joseph's Hospital	Inpatient
St Vincent's Hospital, Sydney	Inpatient and community
Tamworth Base Hospital	Inpatient
Tamworth Nundle Community Health Service	Community
Toronto Private Hospital	Inpatient
Wauchope District Memorial Hospital	Inpatient
Wollongong Hospital – Consult	Inpatient
Wolper Jewish Hospital	Inpatient
Wyong Hospital	Inpatient

1 Benchmark summary for NSW Services

Table 2 Summary of outcome measures by setting of care

Outcome measure		Benchmark	Inpatient		Community		Benchmark Reference No.
			%	BM met?	%	BM met?	
Timely commencement of palliative care							
Care commencing within two days of the patient being ready		90%	97.0	Yes	85.2	No	1
Responsiveness in managing patients with urgent needs							
Patients unstable for three days or less		90%	88.8	No	57.9	No	2
Symptoms & problems in the absent to mild range at phase end							
Anticipatory care *when patient symptoms or problems are in the absent to mild range at phase start*	Pain (clinician reported)	90%	90.1	Yes	82.6	No	3.1
	Pain (patient reported)		89.9	No	82.2	No	3.3
	Fatigue (patient reported)		92.8	Yes	79.5	No	3.5
	Breathing problems (patient reported)		95.1	Yes	92.0	Yes	3.7
	Family/carer problems (clinician reported)		92.2	Yes	82.3	No	3.9
Responsive care *when patient symptoms or problems are in the moderate to severe range at phase start*	Pain (clinician reported)	60%	70.9	Yes	66.3	Yes	3.2
	Pain (patient reported)		66.0	Yes	63.5	Yes	3.4
	Fatigue (patient reported)		66.4	Yes	59.5	No	3.6
	Breathing problems (patient reported)		65.3	Yes	57.1	No	3.8
	Family/carer problems (clinician reported)		64.3	Yes	56.7	No	3.10
Casemix adjusted outcomes (change scores)			Score	BM met?	Score	BM met?	
Clinician reported problems (PCPSS)	Pain	0.0	0.09	Yes	-0.09	No	4.1
	Other symptoms		0.25	Yes	-0.01	No	4.2
	Family/carer problems		0.20	Yes	0.02	Yes	4.3
	Psychological/spiritual problems		0.21	Yes	0.02	Yes	4.4
Patient reported symptom distress (SAS)	Pain	0.0	0.29	Yes	-0.12	No	4.5
	Nausea		0.16	Yes	-0.05	No	4.6
	Breathing problems		0.28	Yes	0.05	Yes	4.7
	Bowel problems		0.28	Yes	-0.02	No	4.8

2 Patient outcomes in more detail

2.1 Timely commencement of palliative care

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (All services are being benchmarked together).

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following, date ready for care.

Table 3   Time from date patient is ready for care to episode start by setting of care

Time (in days)	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Same day	5,247	92.4	20,517	92.6	2,872	81.5	15,747	83.2
Following day	259	4.6	1,022	4.6	129	3.7	803	4.2
2-7	141	2.5	535	2.4	242	6.9	1,380	7.3
8-14	18	0.3	46	0.2	90	2.6	421	2.2
15 +	11	0.2	42	0.2	191	5.4	568	3.0
Average	1.1	-	1.1	-	3.7	-	2.6	-
Median	1	-	1	-	1	-	1	-

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Interpretation hint:

Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix D.

Figure 1   Time from date patient is ready for care to episode start, NSW services compared to all services (BM1)

a. National benchmark profile for BM1

Timely admission to service
90% of patients care starts the day of or the day after the date ready for care

Percentage of episodes

Services ordered from highest to lowest score

b. Outcomes over time for BM1

Inpatient   Community

Percentage

Key: National service profile — Benchmark

NSW services:
● Inpatient   ▲ Community   ■ National results
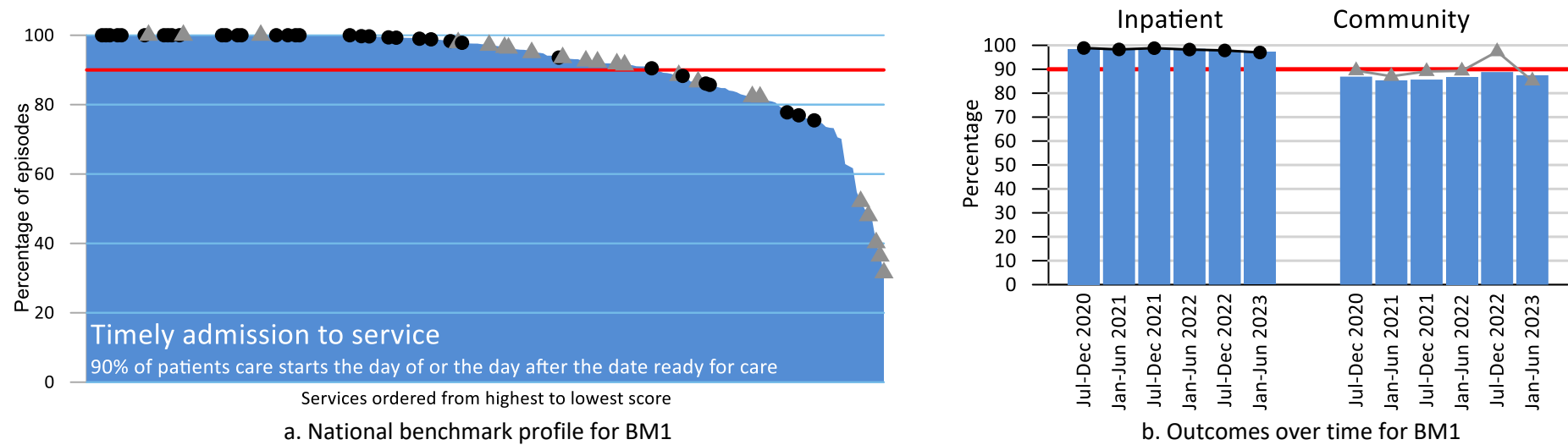
Note: Only services with 10 or more valid assessments are included in the above graphs.

2.2 Responsiveness in managing patients with urgent clinical needs

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and/or
- a patient experiences a rapid increase in the severity of an existing problem, and/or
- a patient's family/carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom/crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

Benchmark 2: This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for three days or less.

Table 4   Time in unstable phase by setting of care

Time in unstable phase	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Same day	198	7.1	521	8.0	246	17.6	1,641	32.9
1 day	1,633	58.5	3,649	55.8	340	24.3	1,429	28.6
2 days	445	15.9	1,163	17.8	134	9.6	489	9.8
3 days	203	7.3	532	8.1	91	6.5	281	5.6
4 − 5 days	204	7.3	414	6.3	122	8.7	277	5.6
6 − 7 days	58	2.1	143	2.2	92	6.6	192	3.8
8 − 14 days	33	1.2	81	1.2	160	11.4	283	5.7
15 days +	18	0.6	34	0.5	216	15.4	398	8.0
Total	2,792	100.0	6,537	100.0	1,401	100.0	4,990	100.0
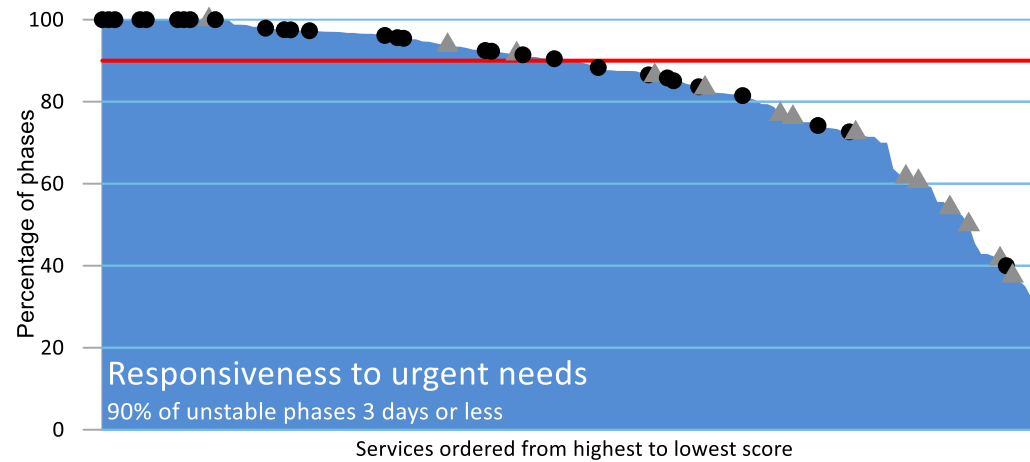
a. National benchmark profile for BM2

b. Outcomes over time for BM2

Responsiveness to urgent needs
90% of unstable phases 3 days or less

Services ordered from highest to lowest score

Key:　　National service profile　　——　Benchmark　　NSW services:　　● Inpatient　　▲ Community　　■ National results
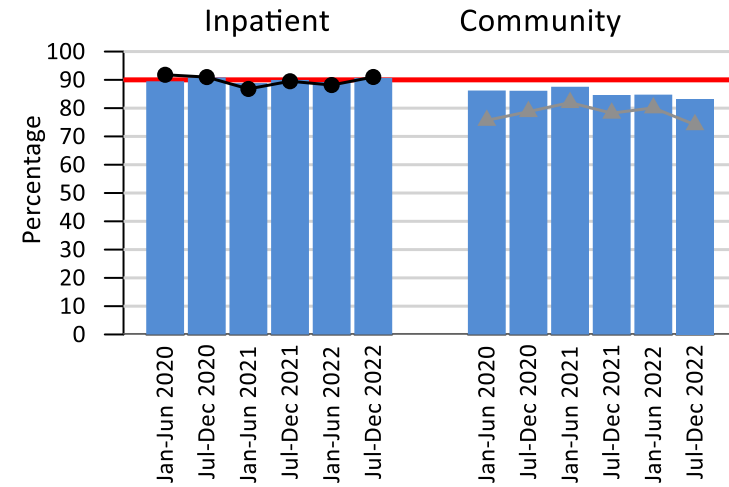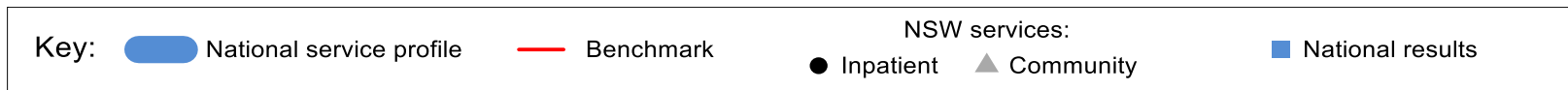
Note: Only services with 10 or more valid assessments are included in the above graphs.

2.3 Symptoms & problems in the absent to mild range at phase end

The outcome measures presented in this section focus on five symptom and problem areas:

1. Pain - clinician reported severity
2. Pain - patient reported distress
3. Fatigue - patient reported distress
4. Breathing problems - patient reported distress
5. Family/carer problems - clinician reported severity

A positive patient outcome is achieved if the patient and family/carer assessment (using the Symptom Assessment Scale and the Palliative Care Problem Severity Score) has an absent to mild symptom/problem at the end of a palliative care phase. The type of care delivered and the corresponding benchmarks achievement depends on the patient's (or family/carer) level of symptom or problem at start of the phase; start scores in the absent to mild range trigger monitoring and review of care plans and are considered **anticipatory care**, whilst start scores in the moderate to severe range trigger interventions, actions and a change in the patient care plan to respond to needs and are considered **responsive care**.

Anticipatory care

The anticipatory care outcome measures and benchmarks relate to patients who have absent or mild symptom/problem at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild symptom/problem. Table 5 summarises the number of patient phases starting with absent to mild symptom/problem, and the percentage of those ending in the absent to mild range.

Table 5   Achieving absent to mild symptoms/problems at phase end, when absent to mild at start

Symptom/problem[a]	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N[b]	%	N[b]	%	N[b]	%	N[b]	%
Pain (clinician reported)	8,905	90.1	26,423	90.8	6,708	82.6	28,758	85.7
Pain (patient reported)	7,751	89.9	22,714	90.6	6,499	82.2	28,478	85.9
Fatigue (patient reported)	8,246	92.8	23,413	93.1	6,077	79.5	24,432	83.1
Breathing problems (patient reported)	8,747	95.1	25,685	95.7	7,177	92.0	29,051	93.4
Family/carer problems (clinician reported)	9,221	92.2	24,940	93.0	6,593	82.3	25,654	83.4

a. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with **absent to mild** symptom/problem.

Responsive care

The responsive care outcome measure and benchmarks relate to patients, and/or family/carer, who have been assessed with moderate or severe symptoms/problems at the start of their phase of palliative care. Achieving an absent/mild symptom or problem outcome at phase end has been identified as more clinically challenging. In order to meet this benchmark, 60% of these patient phases must end with the patient experiencing absent or mild symptom/problem.

Table 6 summarises the number of patient phases assessed as starting with moderate to severe symptom/problem and of those, the percentage ending in the absent to mild range.

Table 6   **Achieving absent to mild symptoms/problems at phase end, when moderate to severe at start**

Symptom/problem[a]	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N[b]	%	N[b]	%	N[b]	%	N[b]	%
Pain (clinician reported)	1,974	70.9	6,218	65.8	1,548	66.3	5,898	59.0
Pain (patient reported)	2,005	66.0	6,127	61.2	1,710	63.5	6,110	56.9
Fatigue (patient reported)	1,466	66.4	5,308	57.6	2,072	59.5	8,625	47.4
Breathing problems (patient reported)	986	65.3	3,084	58.3	984	57.1	3,635	49.0
Family/carer problems (clinician reported)	1,481	64.3	3,877	58.2	1,522	56.7	6,226	49.3

a. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with the symptom or problem rated **moderate to severe**.

On the following pages, the results for the anticipatory and responsive care benchmarks are presented together for each of the five symptom and problem domains. The graphs included compare the outcomes achieved by NSW services to those of other individual services nationally, as well as showing any changes in outcomes over time.

Pain (clinician reported problem severity)

Figure 3   **Pain, patients assessed with absent to mild severity at phase end**

a. National service profile for BM3.1
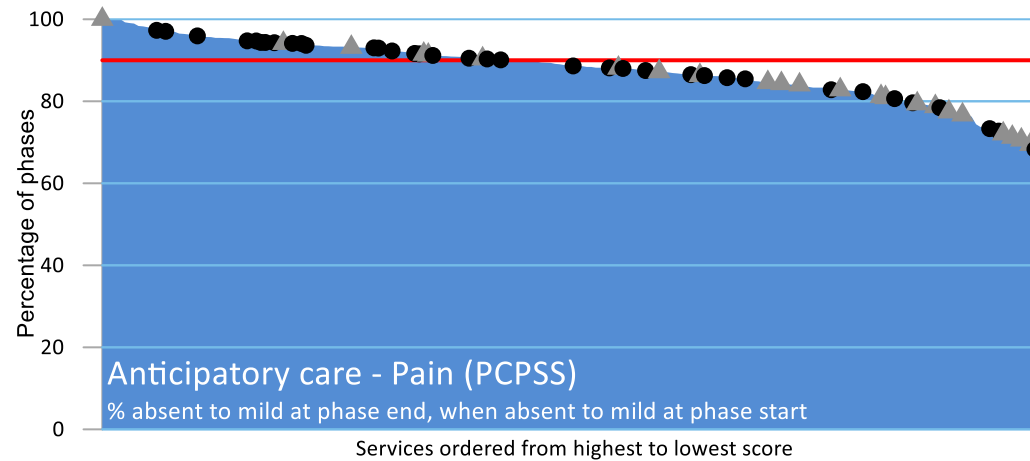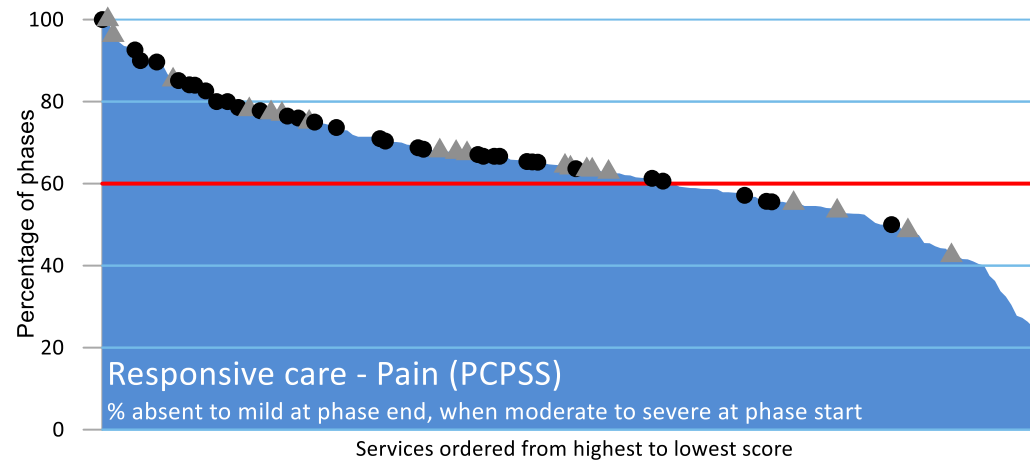
b. Outcomes over time (BM3.1)

c. National service profile for BM3.2
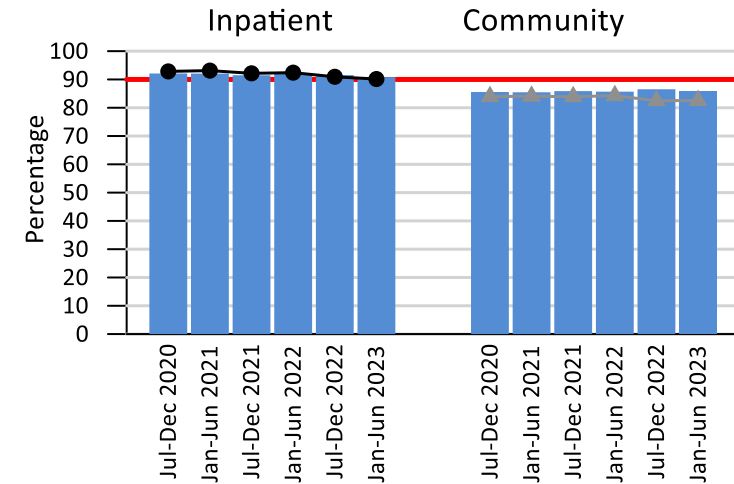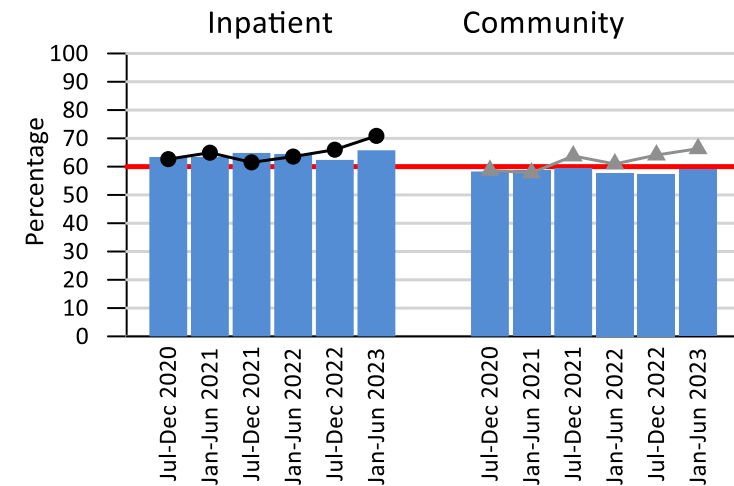
d. Outcomes over time (BM3.2)

Key: National service profile — Benchmark | NSW services: ● Inpatient ▲ Community | ■ National results
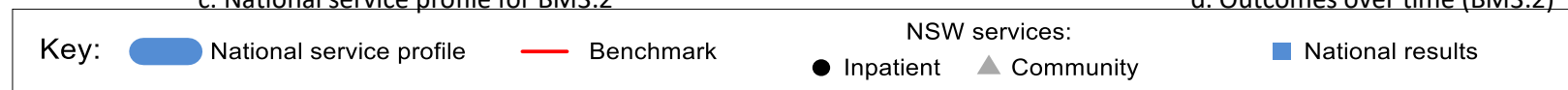
Note: Only services with 10 or more valid assessments are included in the above graphs.

Pain (patient reported distress)

Figure 4   **Pain, patients reporting absent to mild distress at phase end**
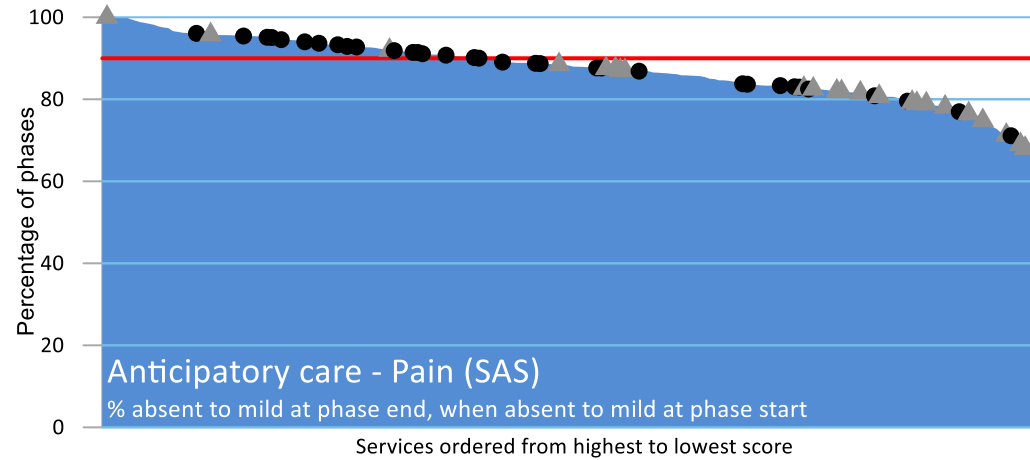
a. National benchmark profile for BM3.3

b. Outcomes over time BM3.3
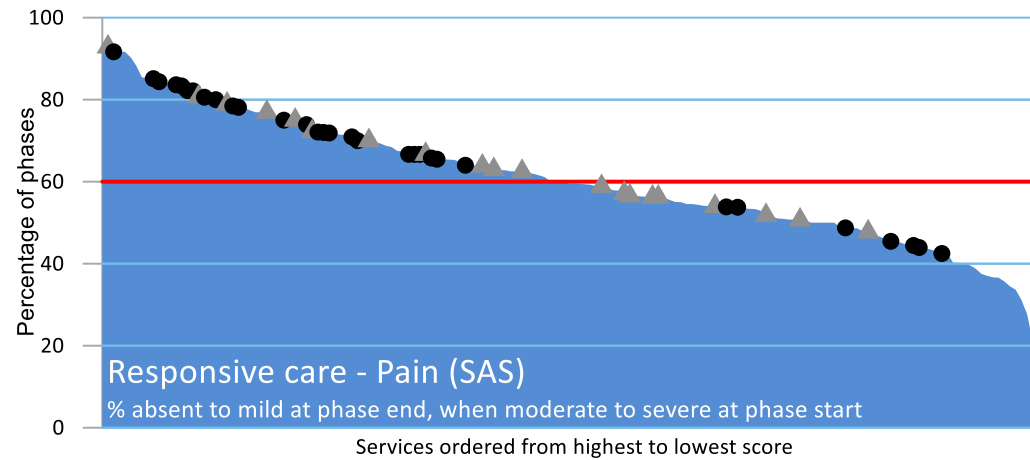
c. National benchmark profile for BM3.4
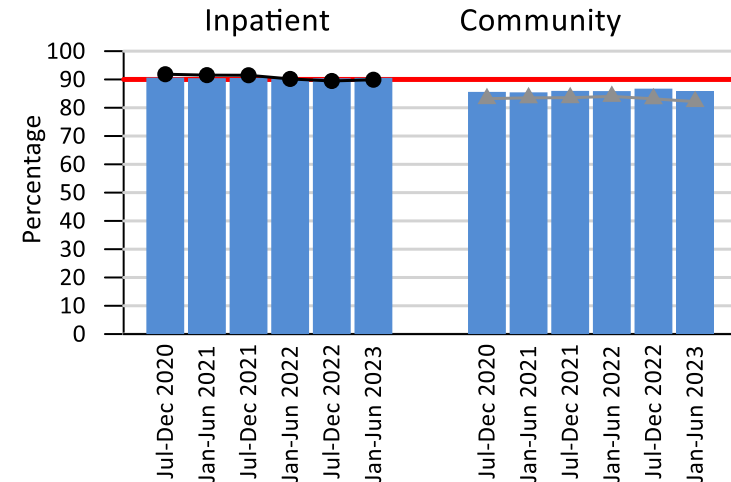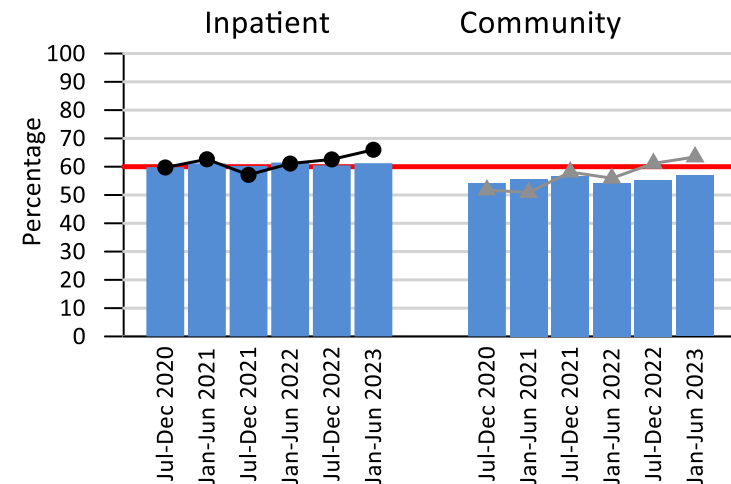
d. Outcomes over time BM3.4
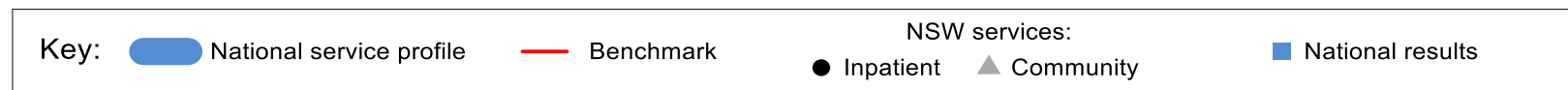
Note: Only services with 10 or more valid assessments are included in the above graphs.

Fatigue (patient reported distress)

Figure 5 **Fatigue, patients reporting absent to mild distress at phase end**
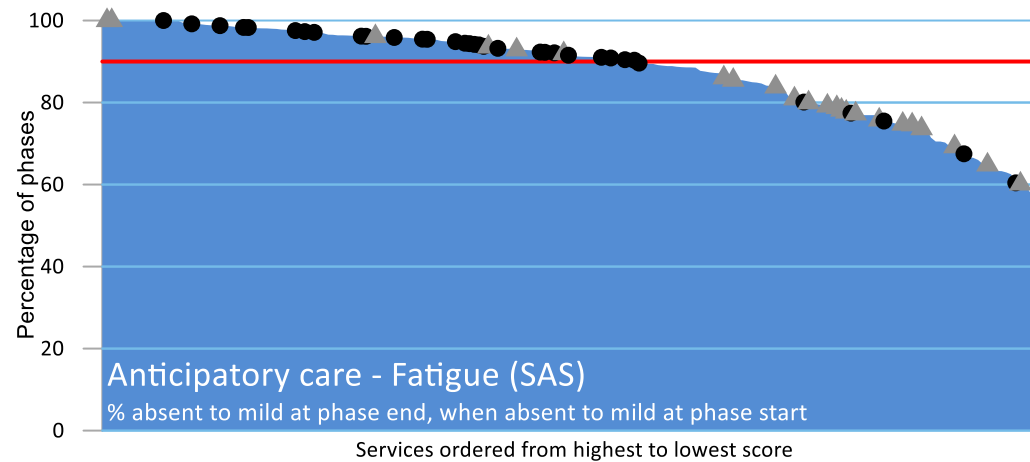
a. National benchmark profile for BM3.5
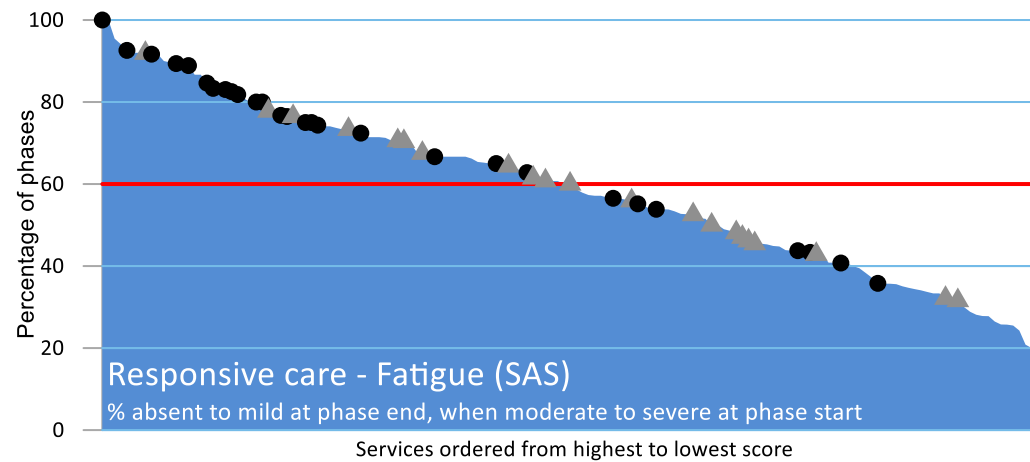
b. Outcomes over time BM3.5

c. National benchmark profile for BM3.6
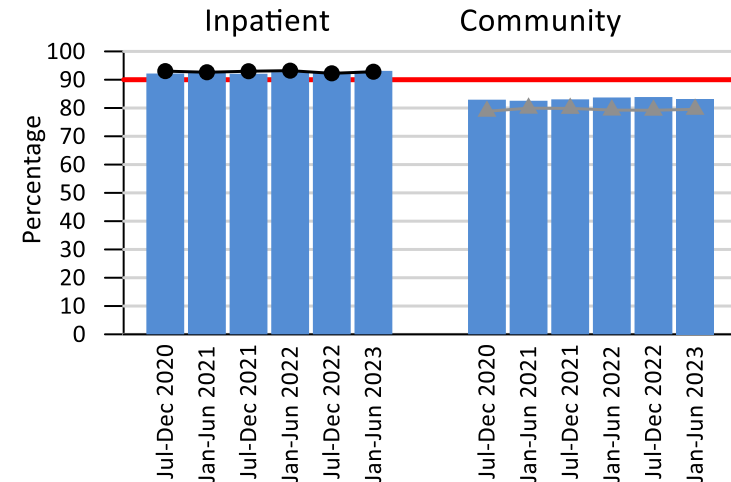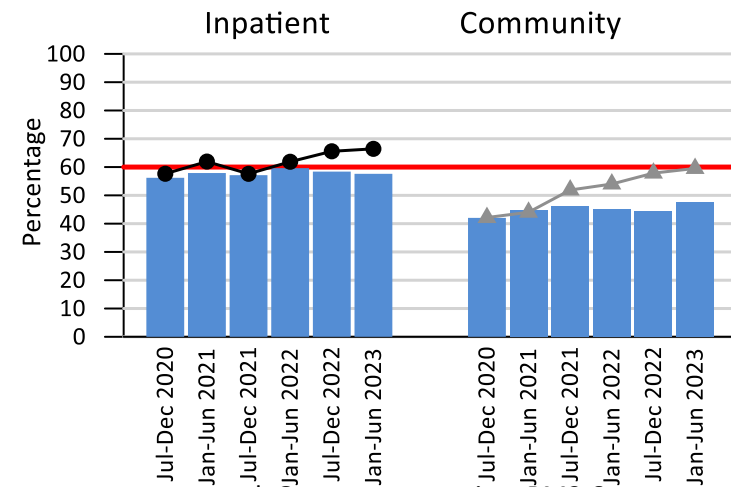
d. Outcomes over time BM3.6

Key: National service profile — Benchmark
NSW services: ● Inpatient ▲ Community National results
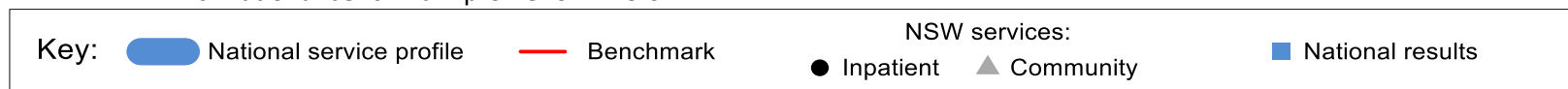
Note: Only services with 10 or more valid assessments are included in the above graphs.

Breathing problems (patient reported distress)

Figure 6 **Breathing problems, patients reporting absent to mild distress at phase end**

Anticipatory care - Breathing problems (SAS)
% absent to mild at phase end, when absent to mild at phase start

Services ordered from highest to lowest score

a. National benchmark profile for BM3.7

b. Outcomes over time BM3.7

Responsive care - Breathing problems (SAS)
% absent to mild at phase end, when moderate to severe at phase start

Services ordered from highest to lowest score
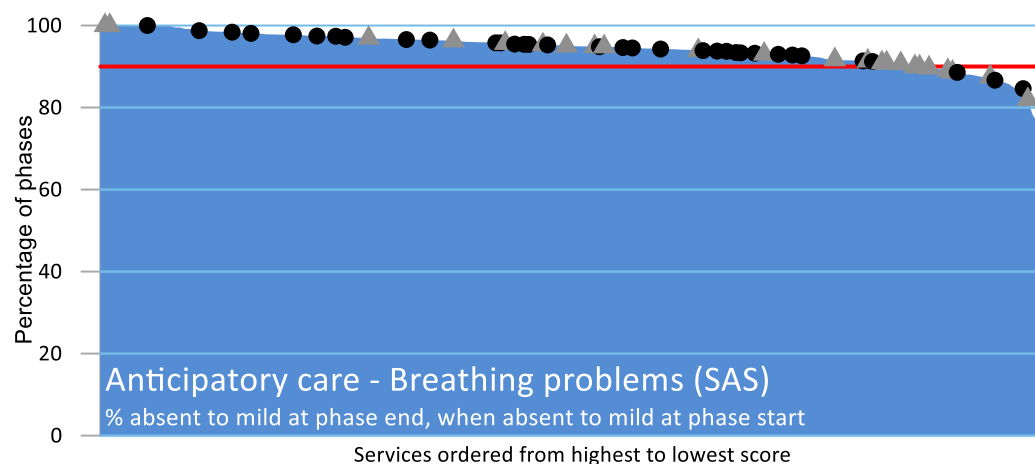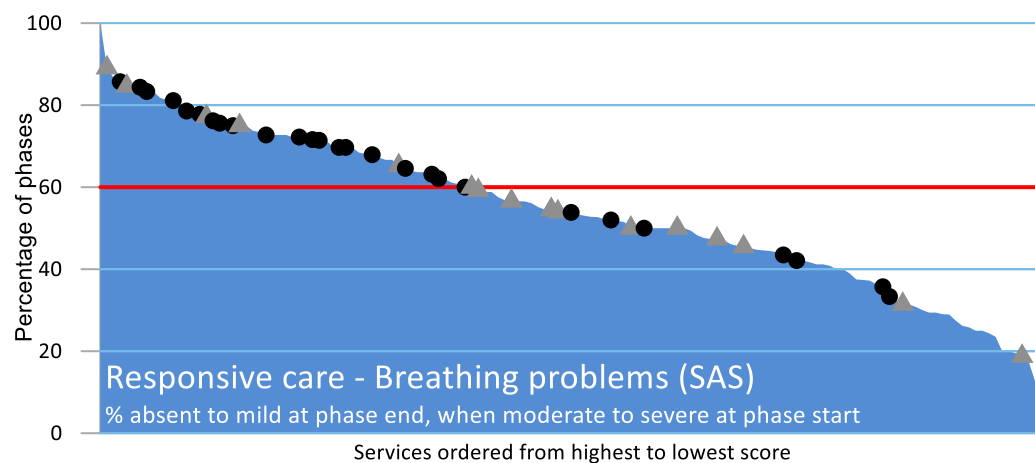
c. National benchmark profile for BM3.8
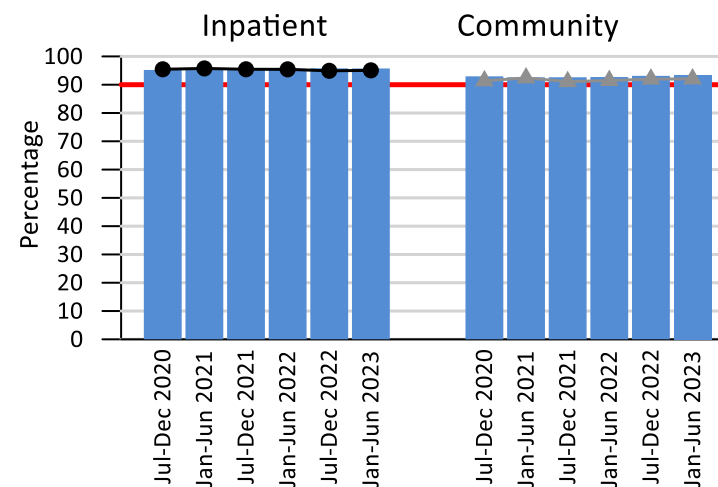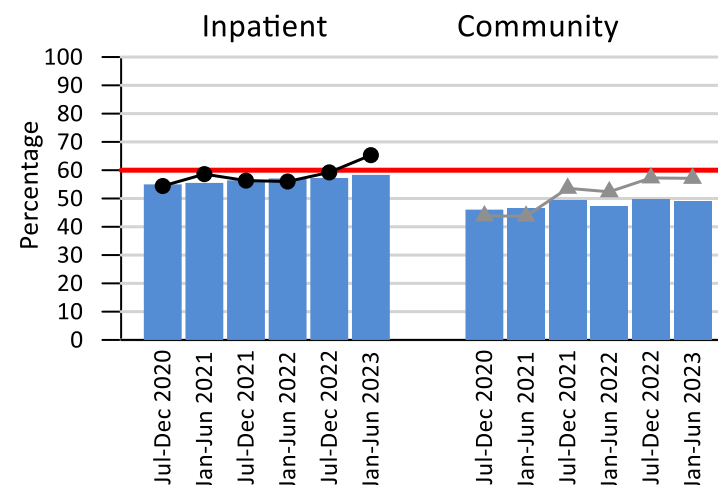
d. Outcomes over time BM3.8

Key: National service profile — Benchmark

NSW services:
● Inpatient ▲ Community ■ National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

Family/carer problems (clinician reported problem severity)

Figure 7 **Family/carer problems, family/carer assessed with absent to mild problem severity at phase end**
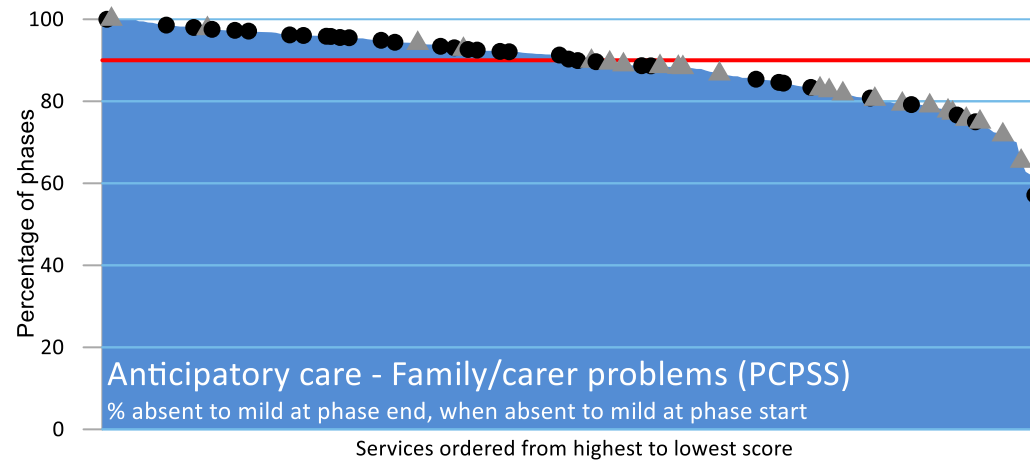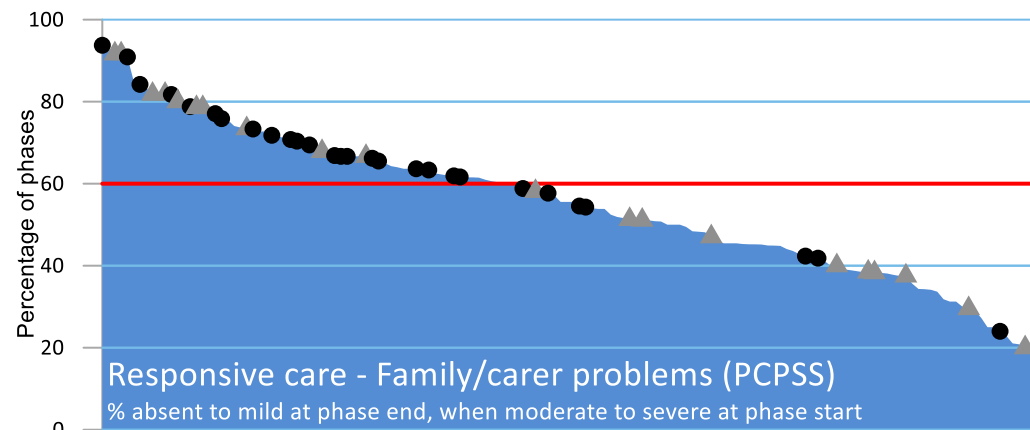
Anticipatory care - Family/carer problems (PCPSS)
% absent to mild at phase end, when absent to mild at phase start

Services ordered from highest to lowest score

a. National benchmark profile for BM3.9

b. Outcomes over time BM3.9

Responsive care - Family/carer problems (PCPSS)
% absent to mild at phase end, when moderate to severe at phase start

Services ordered from highest to lowest score

c. National benchmark profile for BM3.10

d. Outcomes over time BM3.10

Key: National service profile — Benchmark

NSW services: ● Inpatient ▲ Community ■ National results
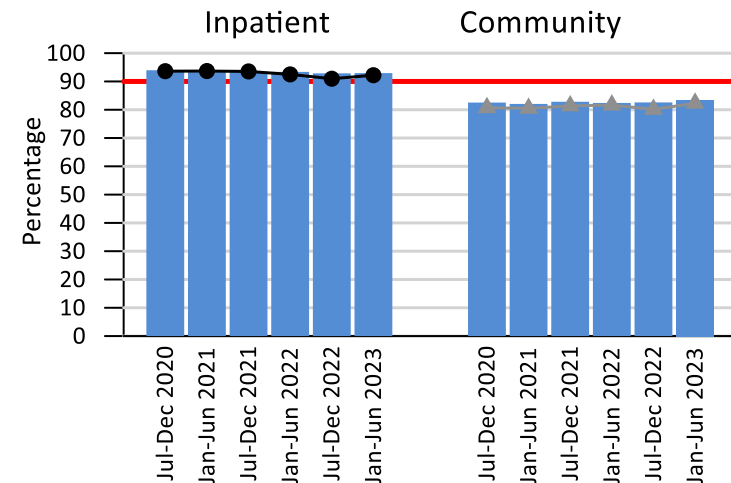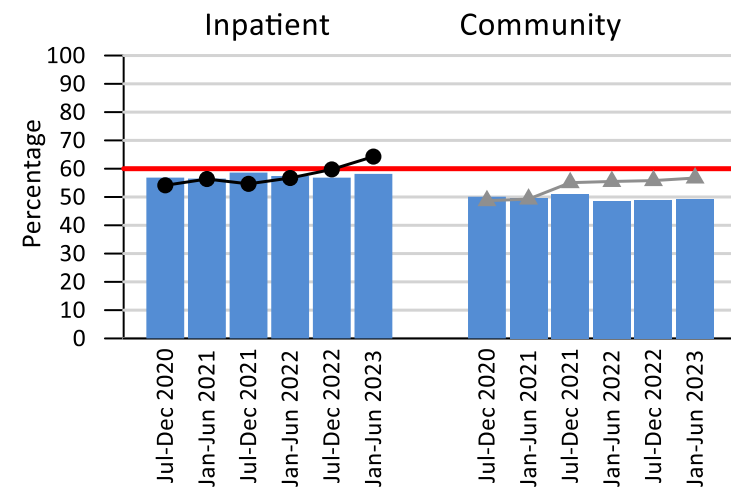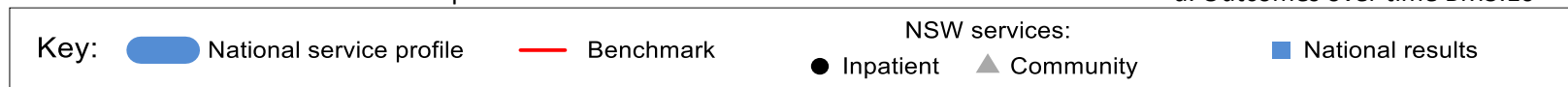
Note: Only services with 10 or more valid assessments are included in the above graphs.

2.4 Casemix adjusted outcomes

Outcome measure 4 includes a suite of eight casemix adjusted scores used to compare the change in symptoms for similar patients. Patients in the same phase who started with the same level of symptom have their change in symptom compared to the reference period (January to June 2014).

Table 7   **Casemix adjusted outcomes – inpatient setting**

Clinical tool	Symptom/problem	NSW Services				All services			
		Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)	Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)
PCPSS	**Pain**	0.09	10,879	6,699	61.6	0.09	32,641	20,160	61.8
Clinician	**Other symptoms**	0.25	10,875	8,249	75.9	0.25	31,987	24,456	76.5
reported	**Family/carer**	0.20	10,702	7,818	73.1	0.21	28,817	21,519	74.7
severity	**Psychological/spiritual**	0.21	10,839	7,250	66.9	0.21	32,307	21,457	66.4
SAS	**Pain**	0.29	9,756	6,534	67.0	0.29	28,841	19,344	67.1
Patient	**Nausea**	0.16	9,717	8,379	86.2	0.19	28,730	25,307	88.1
reported	**Breathing problems**	0.28	9,733	7,742	79.5	0.30	28,769	23,095	80.3
distress	**Bowel problems**	0.28	9,729	7,761	79.8	0.30	28,672	23,327	81.4

The Casemix adjusted scores are calculated relative to a baseline reference period. A Casemix adjusted score:

- **greater than 0** means that on average NSW patients' outcomes were **better than similar patients** in the reference period
- **less than 0** means that on average, NSW patients' outcomes were **worse than similar patients** in the reference period
- **equal to 0** means that on average, NSW patients' outcomes were **about the same as similar patients** in the reference period

Table 8   Casemix adjusted outcomes – community setting

Clinical tool	Symptom /problem	NSW Services				All services			
		Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)	Casemix adjusted score	Phases included (N)	Phases at or above baseline (N)	Phases at or above baseline (%)
PCPSS	**Pain**	-0.09	8,256	4,310	52.2	-0.05	34,656	18,533	53.5
Clinician	**Other symptoms**	-0.01	8,276	5,320	64.3	0.03	33,770	22,355	66.2
reported	**Family/carer**	0.02	8,115	5,445	67.1	0.02	31,880	20,961	65.7
severity	**Psychological/spiritual**	0.02	8,191	4,523	55.2	0.04	33,831	18,226	53.9
SAS	**Pain**	-0.12	8,209	4,785	58.3	-0.06	34,588	20,276	58.6
Patient	**Nausea**	-0.05	8,133	6,357	78.2	-0.01	32,889	26,426	80.3
reported	**Breathing problems**	0.05	8,161	5,594	68.5	0.09	32,686	23,147	70.8
distress	**Bowel problems**	-0.02	8,108	5,557	68.5	0.04	32,343	23,171	71.6

a. Pain (4.1)   b. Other symptoms (4.2)   c. Family/carer (4.3)   d. Psychological/spiritual (4.4)

e. Pain (4.1)   f. Other symptoms (4.2)   g. Family/carer (4.3)   h. Psychological/spiritual (4.4)

Figure 9   **Trends in casemix adjusted outcomes - Symptom Assessment Scale (SAS)**

a. Pain (BM 4.5)

b. Nausea (BM 4.6)

c. Breathing problems (BM 4.7)

d. Bowel problems (BM 4.8)

e. Pain (4.5)

f. Nausea (4.6)

g. Breathing problems (4.7)

h. Bowel problems (4.8)
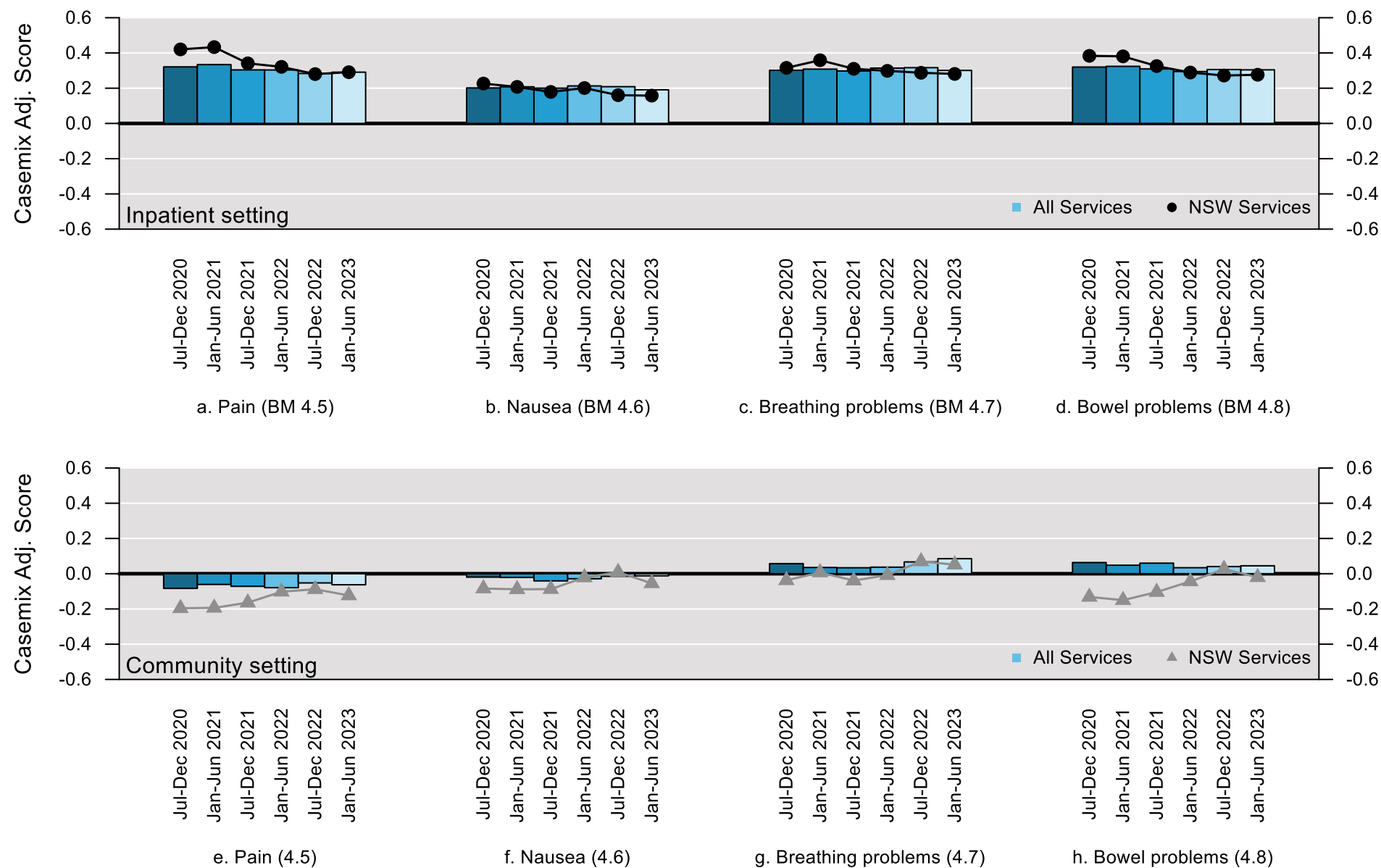
3   Patient characteristics

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family and carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 9 shows the sex for the patients in NSW services and all participating PCOC services.

Table 9   Sex

Sex	NSW Services		All services	
	N	%	N	%
Male	4,759	52.3	18,996	51.7
Female	4,329	47.6	17,751	48.3
Not stated/Inadequately described/Intersex	7	0.1	25	0.1
Total	9,095	100.0	36,772	100.0

Table 10 shows the Indigenous status for the patients in NSW services and all participating PCOC services.

Table 10   Indigenous status

Indigenous status	NSW Services		All services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	167	1.8	711	1.9
Torres Strait Islander but not Aboriginal origin	s	s	30	0.1
Both Aboriginal and Torres Strait Islander origin	s	s	54	0.1
Neither Aboriginal nor Torres Strait Islander origin	8,776	96.5	34,775	94.6
Not stated/inadequately described	144	1.6	1,202	3.3
Total	9,095	100.0	36,772	100.0

Table 11 **Country of birth**

Country of birth	NSW Services		All services	
	N	%	N	%
Australia	5,538	60.9	23,724	64.5
England	570	6.3	2,324	6.3
India	70	0.8	304	0.8
China	305	3.4	588	1.6
New Zealand	143	1.6	643	1.7
Philippines	56	0.6	158	0.4
Vietnam	97	1.1	282	0.8
South Africa	61	0.7	192	0.5
Malaysia	26	0.3	150	0.4
Italy	311	3.4	1,339	3.6
Sri Lanka	29	0.3	123	0.3
Scotland	97	1.1	443	1.2
Nepal	s	s	7	0.0
United States of America	s	s	85	0.2
Germany	87	1.0	369	1.0
All other countries	1,530	16.8	5,194	14.1
Not stated	150	1.6	847	2.3
Total	9,095	100.0	36,772	100.0

The tables on this page show the country of birth and the preferred language respectively for the patients in NSW services and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 11 is in descending order of the most frequent country of birth according to the 2021 Census (e.g. India was the third most common country of birth in the 2021 Census). The same approach has been taken with Table 12 (e.g. Arabic was the fourth most frequently spoken language in the 2021 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 12 **Preferred language**

Language	NSW Services		All services	
	N	%	N	%
English	7,673	84.4	32,631	88.7
Chinese[a]	329	3.6	658	1.8
Hindi[b]	29	0.3	118	0.3
Arabic[c]	112	1.2	263	0.7
Vietnamese[d]	75	0.8	222	0.6
Filipino/Indonesian[e]	25	0.3	56	0.2
Tamil/Malayalam[f]	s	s	17	0.0
Spanish[g]	71	0.8	138	0.4
Greek	115	1.3	467	1.3
Italian	163	1.8	616	1.7
Macedonian/Croatian[h]	105	1.2	293	0.8
African languages	s	s	27	0.1
Korean	44	0.5	55	0.1
Samoan/Tongan[i]	18	0.2	45	0.1
Australian Indigenous languages	10	0.1	33	0.1
All other languages	258	2.8	646	1.8
Not stated	59	0.6	487	1.3
Total	9,095	100.0	36,772	100.0

Also includes
(a) Cantonese, Hakka, Mandarin, Wu and Min Nan
(b) Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, and Fijian Hindustani
(c) Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, and Mandaean (Mandaic)
(d) Khmer and Mon
(e) Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo, Javanese, and Pampangan
(f) Kannada, Telugu, and Tulu
(g) Catalan and Portuguese
(h) Bosnian, Bulgarian, Serbian, and Slovene
(i) Fijian, Gilbertese, Maori, Nauruan, Niue, Rotuman, Tokelauan, Tuvaluan, and Yapese

Table 13 and Table 14 present a breakdown of malignant and non-malignant diagnosis for the patients in NSW services and at the national level. Diagnosis is the principal life-limiting illness responsible for the patient requiring palliative care.

Diagnosis was not stated for 17 (0.2%) patients in NSW services and was not stated for 325 (0.9%) patients nationally.

Table 13   Principal diagnosis - malignant

Diagnosis	NSW Services			All services		
	N	% of malignant diagnoses	% of all diagnoses	N	% of malignant diagnoses	% of all diagnoses
Bone and soft tissue	70	1.1	0.8	345	1.5	1.0
Breast	426	7.0	4.7	1,656	7.1	4.6
CNS	132	2.2	1.5	558	2.4	1.5
Colorectal	623	10.2	6.9	2,302	9.9	6.4
Other GIT	660	10.8	7.3	2,359	10.1	6.5
Haematological	449	7.3	4.9	1,628	7.0	4.5
Head and neck	286	4.7	3.2	1,199	5.2	3.3
Lung	1,193	19.5	13.1	4,592	19.7	12.7
Pancreas	479	7.8	5.3	1,745	7.5	4.8
Prostate	380	6.2	4.2	1,567	6.7	4.3
Other urological	321	5.2	3.5	1,043	4.5	2.9
Gynaecological	309	5.1	3.4	1,160	5.0	3.2
Skin	253	4.1	2.8	868	3.7	2.4
Unknown primary	232	3.8	2.6	668	2.9	1.8
Other primary malignancy	268	4.4	3.0	1,110	4.8	3.1
Malignant – Not further defined	35	0.6	0.4	463	2.0	1.3
All malignant diagnoses	6,116	100.0	67.4	23,263	100.0	64.4

Table 14   Principal diagnosis - non-malignant

Diagnosis	NSW Services			All services		
	N	% of non-malignant diagnoses	% of all diagnoses	N	% of non-malignant diagnoses	% all diagnoses
Cardiovascular disease	366	12.4	4.0	1,794	13.9	5.0
HIV/AIDS	s	s	s	6	0.0	0.0
End stage kidney disease	207	7.0	2.3	932	7.2	2.6
Stroke	156	5.3	1.7	796	6.2	2.2
Motor neurone disease	97	3.3	1.1	366	2.8	1.0
Alzheimer's dementia	110	3.7	1.2	832	6.5	2.3
Other dementia	259	8.7	2.9	1,208	9.4	3.3
Other neurological disease	191	6.4	2.1	724	5.6	2.0
Respiratory failure	564	19.0	6.2	2,206	17.1	6.1
End stage liver disease	44	1.5	0.5	355	2.8	1.0
Diabetes & its complications	s	s	s	67	0.5	0.2
Sepsis	159	5.4	1.8	682	5.3	1.9
Multiple organ failure	105	3.5	1.2	337	2.6	0.9
Other non-malignancy	674	22.8	7.4	2,191	17.0	6.1
Non-malignant – Not further defined	18	0.6	0.2	388	3.0	1.1
All non-malignant	2,962	100.0	32.6	12,884	100.0	35.6

Figure 10 shows the proportion of patients with malignant and non-malignant diagnoses for this report compared to the previous five reports.

Figure 10   Principal diagnosis for NSW Services over time
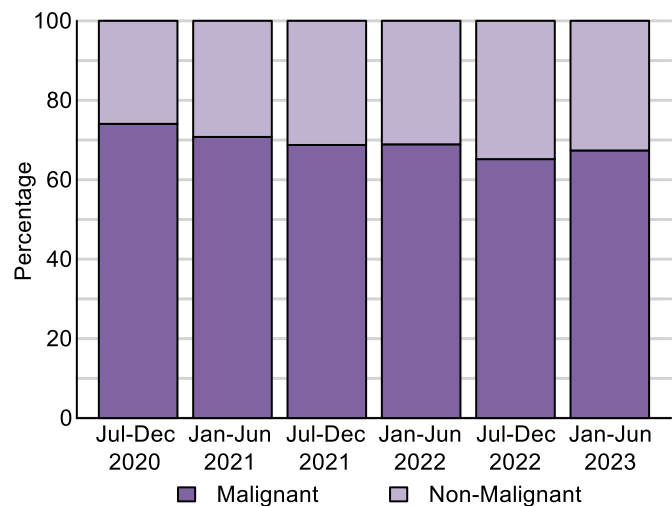
Table 15 shows the breakdown of patient deaths in NSW services and nationally for the reporting period. All inpatient deaths are reported in the hospital/hospice category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 15   Place of death

Place of death	NSW Services		All services	
	N	%	N	%
Private residence	579	14.5	3,156	18.9
Residential aged care facility	256	6.4	1,756	10.5
Hospital/hospice	3,140	78.5	11,529	68.9
Not stated/inadequately described	24	0.6	285	1.7
Total	3,999	100.0	16,726	100.0

4   Episodes of palliative care

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as an inpatient or community patient.

An episode of palliative care starts on the date the comprehensive palliative care assessment is completed using the five PCOC clinical assessment tools and documented in the patient medical record.

An episode of palliative care ends when:
- the patient is formally separated from the current setting of care (e.g. from community to inpatient) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 16 presents the number and percentage of episodes by age group and sex for the patients seen by NSW services and at the national level. Age has been calculated as at episode start.

Table 16   **Patient's age by sex**

Age group	NSW Services				All services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	s	s	0	0.0	23	0.1	10	0.0
15 - 24	s	s	s	s	63	0.3	26	0.1
25 - 34	17	0.3	s	s	137	0.6	173	0.8
35 - 44	60	1.1	94	1.8	369	1.6	477	2.2
45 - 54	210	3.8	295	5.7	1,162	4.9	1,184	5.4
55 - 64	652	11.7	560	10.9	2,710	11.5	2,431	11.1
65 - 74	1,224	22.0	942	18.3	5,129	21.8	4,164	19.0
75 - 84	1,664	29.9	1,380	26.9	7,005	29.7	5,753	26.3
85 +	1,303	23.4	1,466	28.5	5,391	22.9	6,233	28.5
Unknown	424	7.6	364	7.1	1,580	6.7	1,434	6.6
Total	5,564	100.0	5,135	100.0	23,569	100.0	21,885	100.0

Note: Records where sex was not stated or inadequately described are excluded from the table.

Referral source refers to the facility from where the patient was referred for each episode of care. Table 17 presents referral source by setting of care.

Table 17   **Source of referral**

Referral source	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Public hospital	4,422	75.9	16,467	74.8	1,629	52.0	6,332	39.0
Private hospital	239	4.1	1,673	7.6	228	7.3	1,641	10.1
Outpatient clinic	25	0.4	133	0.6	28	0.9	265	1.6
General medical practitioner	88	1.5	190	0.9	685	21.9	2,475	15.2
Specialist medical practitioner	253	4.3	443	2.0	412	13.2	1,373	8.5
Community-based palliative care agency	755	13.0	2,570	11.7	27	0.9	583	3.6
Community-based service	s	s	33	0.1	s	s	138	0.9
Residential aged care facility	s	s	71	0.3	s	s	1,637	10.1
Self, carer(s), family or friends	17	0.3	123	0.6	41	1.3	414	2.6
Other	15	0.3	236	1.1	31	1.0	1,348	8.3
Not stated/inadequately described	4	0.1	75	0.3	6	0.2	27	0.2
Total	5,826	100.0	22,014	100.0	3,131	100.0	16,233	100.0

Note: Only episodes starting during the reporting period are included.

Table 18   Referral source for NSW Services over time

Referral source	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=6,418	N=7,132	N=8,261	N=7,377	N=6,275	N=8,957
Public hospital	58.0	62.9	65.0	67.3	67.9	67.6
Private hospital	6.3	6.4	5.5	4.7	4.9	5.2
Outpatient clinic	0.8	0.6	0.7	0.3	0.5	0.6
General practitioner	7.8	7.2	7.0	7.4	8.0	8.6
Specialist medical practitioner	6.1	6.0	5.6	6.5	7.2	7.4
Community palliative care service	16.4	13.2	13.3	11.4	9.2	8.7
Community generalist service	0.7	0.5	0.4	0.4	0.4	0.3
Residential aged care facility	0.3	0.3	0.2	0.2	0.3	0.2
Self, carer(s), family, friends	1.0	1.2	0.9	0.7	0.4	0.6
Other	0.6	0.8	1.0	0.6	0.7	0.5
Not stated/inadequately described	2.1	1.0	0.4	0.4	0.3	0.1
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Only episodes starting during the reporting period are included.

Table 19 gives a summary of the length of episodes for patients in NSW services and nationally.

Table 19 **Length of episode (in days) summary by setting of care**

Length of episode	Inpatient		Community	
	NSW Services	All services	NSW Services	All services
Average length of episode	9.8	8.3	43.3	39.1
Median length of episode	6.0	4.0	34.0	28.0

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 20 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 20 **Length of episode by setting of care**

Length of episode (days)	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Same day	373	6.4	2,295	10.3	71	2.0	784	4.2
1-2	1,267	21.8	5,688	25.4	186	5.1	1,053	5.6
3-4	895	15.4	3,565	15.9	162	4.5	965	5.1
5-7	991	17.0	3,582	16.0	239	6.6	1,429	7.6
8-14	1,129	19.4	3,678	16.4	427	11.8	2,225	11.8
15-21	517	8.9	1,587	7.1	344	9.5	1,759	9.3
22-30	286	4.9	931	4.2	274	7.6	1,712	9.1
31-60	295	5.1	830	3.7	625	17.3	3,242	17.2
61-90	51	0.9	140	0.6	369	10.2	1,644	8.7
91 +	14	0.2	77	0.3	924	25.5	4,069	21.5
Total	5,818	100.0	22,373	100.0	3,621	100.0	18,882	100.0

Note: Only episodes ending during the reporting period are included.

Table 21   How inpatient episodes start

Episode start mode	NSW Services		All services	
	N	%	N	%
Admitted from community[1]	3,929	67.4	14,616	66.4
Admitted from another hospital	940	16.1	3,186	14.5
Admitted from acute care in another ward	526	9.0	3,045	13.8
Change from acute care to palliative care – same ward	366	6.3	737	3.3
Other[2]	61	1.0	236	1.1
Not stated/inadequately described	4	0.1	194	0.9
Total	5,826	100.0	22,014	100.0

Note: Only episodes starting during the reporting period are included.

[1] includes: admitted from usual accommodation, admitted from other than usual accommodation.

[2] includes: change of sub-acute/non-acute care type and other categories.

Table 22   How inpatient episodes end

Episode end mode	NSW Services		All services	
	N	%	N	%
Discharged to community[1]	1,871	32.1	6,857	30.6
Discharged to another hospital	428	7.3	1,638	7.3
Death	3,140	53.9	11,529	51.5
Change from palliative care to acute care[2]	111	1.9	207	0.9
Change in sub-acute care type	71	1.2	155	0.7
End of consultative episode – inpatient episode ongoing	43	0.7	1,351	6.0
Other	136	2.3	256	1.1
Not stated/inadequately described	27	0.5	394	1.8
Total	5,827	100.0	22,387	100.0

Note: Only episodes ending during the reporting period are included.

[1] includes: discharged to usual accommodation, discharged to other than usual accommodation.

[2] includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.

Table 23 How inpatient episodes start for NSW Services over time

Episode start mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=3,537	N=4,335	N=5,471	N=5,124	N=4,497	N=5,826
Admitted from community[1]	47.0	53.8	60.3	62.1	66.8	67.4
Admitted from another hospital	30.5	22.4	19.3	18.7	17.1	16.1
Admitted from acute care on another ward	13.8	13.7	12.4	12.1	11.2	9.0
Change from acute care to palliative care – same ward	8.6	9.8	7.4	6.3	3.9	6.3
Other[2]	0.1	0.2	0.6	0.6	1.0	1.0
Not stated/inadequately descried	0.0	0.2	0.1	0.3	0.0	0.1
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Only episodes starting during the reporting period are included.

[1] includes: admitted from usual accommodation, admitted from other than usual accommodation.

[2] includes: change of sub-acute/non-acute care type and other category.

Table 24 How inpatient episodes end for NSW Services over time

Episode end mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=3,745	N=4,536	N=5,598	N=5,275	N=4,562	N=5,827
Discharged to community[1]	30.8	29.2	32.6	29.7	31.3	32.1
Discharged to another hospital	3.9	7.5	7.4	7.7	8.0	7.3
Death	63.8	59.3	54.3	57.7	55.5	53.9
Change from palliative care to acute care[2]	0.6	0.7	1.1	1.5	1.3	1.9
Change in sub-acute care type	0.2	0.4	1.1	1.1	2.0	1.2
End of consultative episode – inpatient episode ongoing	0.0	1.8	1.8	0.3	0.3	0.7
Other	0.5	1.0	1.6	1.7	1.3	2.3
Not stated/inadequately described	0.2	0.1	0.0	0.2	0.4	0.5
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Only episodes ending during the reporting period are included.

[1] includes: discharged to usual accommodation, discharged to other than usual accommodation.

[2] includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.

Table 25   How community episodes start

Episode start mode	NSW Services		All services	
	N	%	N	%
Admitted from inpatient palliative care	1,004	32.1	4,835	29.8
Other[1]	2,049	65.4	11,247	69.3
Not stated/inadequately described	78	2.5	151	0.9
Total	3,131	100.0	16,233	100.0

Note: Only episodes starting during the reporting period are included.

[1] includes: patient was not transferred from being an overnight patient.

Table 26   How community episodes end

Episode end mode	NSW Services		All services	
	N	%	N	%
Admitted for inpatient palliative care	851	23.5	5,565	29.4
Admitted for inpatient acute care	1,346	37.1	4,422	23.4
Admitted to another palliative care service	30	0.8	219	1.2
Admitted to primary health care	298	8.2	1,523	8.1
Discharged/case closure	158	4.4	1,354	7.2
Death	859	23.7	5,197	27.5
Other	72	2.0	191	1.0
Not stated/inadequately described	10	0.3	435	2.3
Total	3,624	100.0	18,906	100.0

Note: Only episodes ending during the reporting period are included.

Table 27 How community episodes start for NSW Services over time

Episode start mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=2,881	N=2,797	N=2,790	N=2,253	N=1,778	N=3,131
Admitted from inpatient palliative care	28.6	27.9	28.9	28.2	37.3	32.1
Other[1]	71.2	71.3	69.0	70.1	60.4	65.4
Not stated/inadequately described	0.2	0.9	2.1	1.7	2.2	2.5
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Only episodes starting during the reporting period are included.
[1]includes: patient was not transferred from being an overnight admitted palliative care patient

Table 28 How community episodes end for NSW Services over time

Episode end mode (%)	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
	N=3,615	N=3,598	N=3,207	N=2,906	N=2,108	N=3,624
Admitted for inpatient palliative care	22.6	22.9	23.1	23.7	20.9	23.5
Admitted for inpatient acute care	38.8	40.4	36.8	36.8	36.9	37.1
Admitted to another palliative care service	1.2	1.1	0.8	0.8	0.5	0.8
Admitted to primary health care	4.8	5.6	4.8	5.3	4.9	8.2
Discharged/case closure	5.7	6.7	6.1	5.1	5.7	4.4
Death	23.5	21.7	26.8	24.7	29.7	23.7
Other	1.3	1.1	1.2	1.1	1.2	2.0
Not stated/inadequately described	2.1	0.5	0.3	2.5	0.2	0.3
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Only episodes ending during the reporting period are included.

5   Profile of palliative care patient assessments

The palliative care profile of patients is determined using five clinical assessment tools which in combination with each other provides a total picture of patients' trajectory at specific points in time along their journey. These five assessment tools are completed daily for inpatient services, and at each contact for community services. Assessments are reported on admission to the service, at phase change and at discharge from the service. These tools include:

- Palliative care phase – an assessment used to identify a clinically meaningful period in a patient's condition. The five palliative care phases are stable, unstable, deteriorating, terminal and bereavement (PCOC does not report on bereavement phases).
- Palliative Care Problem Severity Score (PCPSS) – a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains being pain, other symptoms, psychological/spiritual and family/carer. The scores are 0 – absent, 1 – mild, 2 – moderate and 3 – severe.
- Symptom Assessment Scale (SAS) – a patient (or proxy) rated tool that assesses the level of distress using a numerical rating scale from 0 – no distress to 10 – worst possible distress for seven symptoms (insomnia, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain).
- Resource Utilisation Groups-Activities of Daily Living (RUG-ADL) – four items (bed mobility, toileting, transfers and eating) to record the level of functional dependence.
- Australia-modified Karnofsky Performance Status (AKPS) – a measure of overall performance status and ability to perform common tasks relating to activity, work and self care. It is a single score between 0 and 100. PCOC does not report 0 (deceased).

5.1   Phase

The palliative care phase identifies a clinically meaningful period in a patient's care. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family or carers. The five palliative care phases are stable, unstable, deteriorating, terminal and bereavement (PCOC does not report on bereavement phases). A patient may move back and forth between the phase types based on assessments and clinical care and they may occur in any sequence. See Appendix F for more information on the definition of palliative care phase.

The patients are assessed using the 5 PCOC assessment tools daily in the inpatient units, or at each visit or phone contact in the community, and are reported on admission to the service, at phase changes and at discharge from the service.

Table 29   Number of patient phases by phase type and setting of care

Phase type	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Stable	4,645	29.2	11,847	24.3	4,737	41.9	17,979	36.4
Unstable	2,792	17.5	6,537	13.4	1,401	12.4	4,990	10.1
Deteriorating	5,616	35.3	19,124	39.2	4,494	39.7	22,333	45.2
Terminal	2,863	18.0	11,238	23.1	682	6.0	4,104	8.3
Total	15,916	100.0	48,746	100.0	11,314	100.0	49,406	100.0

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 30   Average phase length (in days) by phase type and setting of care

Phase type	Inpatient		Community	
	NSW Services	All services	NSW Services	All services
Stable	5.7	5.6	22.5	23.0
Unstable	2.0	1.9	7.4	4.5
Deteriorating	4.2	4.7	11.1	14.5
Terminal	2.0	2.0	2.5	3.2

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

Figure 11 and Figure 12 show the percentage of phases over time. These graphs allow NSW services to identify changes in the profile of your patients' phase type by setting of care over time.

Figure 11   **Patient phase profile over time – inpatient setting**
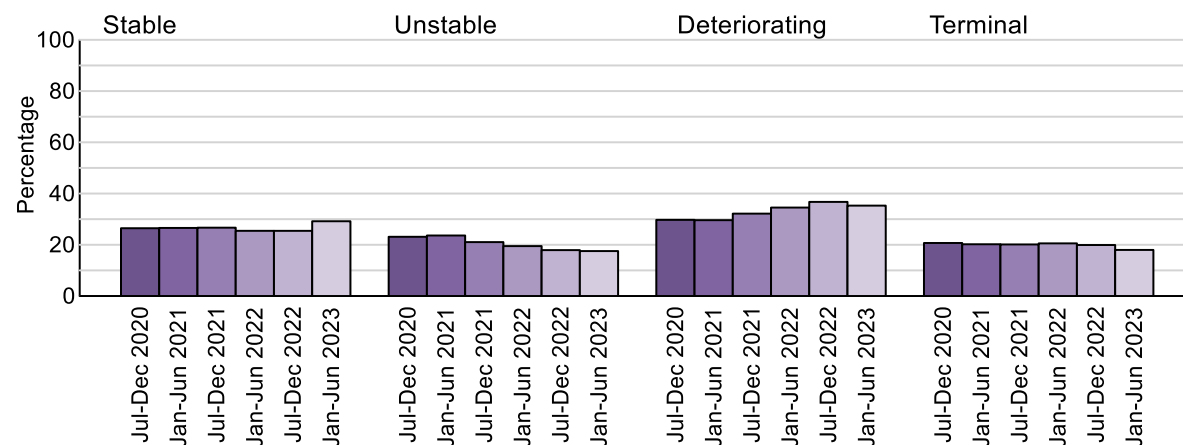
Figure 12   **Patient phase profile over time – community setting**
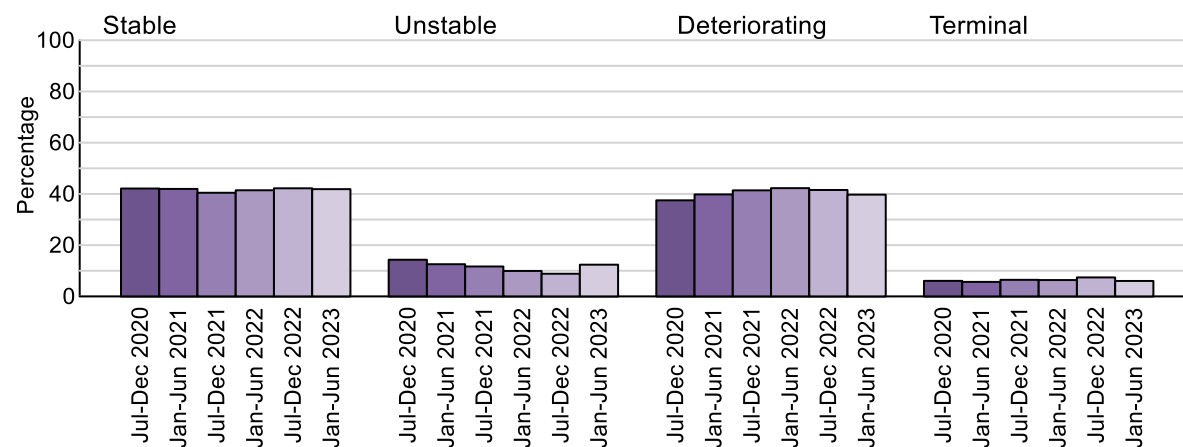
Table 31 presents the patients' first phase type for the episode, both for NSW services and nationally. The first phase of the episode allows you to understand the type of patient, complexity and reason patients are entering NSW services.

Table 31　　　**First phase of episode by setting**

First phase	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Stable	1,158	19.5	3,426	15.3	2,044	52.3	7,235	37.2
Unstable	1,702	28.7	4,175	18.6	340	8.7	1,061	5.5
Deteriorating	2,397	40.4	11,436	51.0	1,426	36.5	10,263	52.8
Terminal	678	11.4	3,384	15.1	98	2.5	881	4.5
Total	5,935	100.0	22,421	100.0	3,908	100.0	19,440	100.0

Note: This table only includes the first phase if the episode has started in the reporting period.

5.2 Palliative Care Problem Severity Score

The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological/spiritual and family/carer). The ratings to assess patients and their family/carer are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 32 shows the percentage of phases that were rated absent, mild, moderate and severe at phase start for each key domain for NSW inpatient setting of care compared to all participating PCOC inpatient services. Table 33 shows the same for NSW community setting of care compared to all participating PCOC community services. Alternative graphical representations of PCPSS profile by phase type are shown in Appendix C.

Table 32 **PCPSS at phase start by phase type – inpatient setting**

Phase type	Problem	NSW Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	49.5	43.6	6.7	0.2	51.2	41.5	6.8	0.5
	Other symptoms	39.8	53.0	6.9	0.2	41.7	50.4	7.6	0.3
	Psychological/spiritual	60.2	35.6	4.0	0.2	56.9	38.2	4.6	0.3
	Family/carer	58.1	36.3	5.1	0.5	58.9	35.5	5.0	0.6
Unstable	Pain	25.6	39.7	27.5	7.3	25.3	36.3	29.8	8.6
	Other symptoms	16.9	48.8	27.7	6.6	18.3	43.5	30.5	7.8
	Psychological/spiritual	38.0	41.5	17.1	3.4	34.8	42.2	19.1	3.9
	Family/carer	39.1	38.8	17.4	4.6	37.0	40.5	18.8	3.7
Deteriorating	Pain	39.0	42.8	16.8	1.4	37.7	42.8	17.8	1.7
	Other symptoms	25.9	51.5	20.7	1.9	25.9	50.5	21.6	1.9
	Psychological/spiritual	46.6	40.4	11.8	1.3	42.8	44.7	11.6	0.9
	Family/carer	40.2	43.4	14.5	1.9	40.5	44.7	13.3	1.5
Terminal	Pain	48.6	37.8	11.8	1.8	44.8	39.8	13.4	1.9
	Other symptoms	42.3	39.5	15.5	2.7	40.4	40.3	16.6	2.6
	Psychological/spiritual	63.3	28.8	6.9	1.0	64.1	28.7	6.4	0.8
	Family/carer	33.3	43.8	19.8	3.1	33.7	46.5	17.1	2.7

Table 33   **PCPSS at phase start by phase type – community setting**

Phase type	Problem	NSW Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	39.3	56.1	4.5	0.1	45.8	49.9	4.2	0.1
	Other symptoms	19.0	72.7	8.1	0.2	25.7	66.6	7.5	0.2
	Psychological/spiritual	41.7	53.9	4.2	0.2	44.6	50.7	4.5	0.2
	Family/carer	41.4	52.1	6.3	0.3	41.6	51.8	6.3	0.3
Unstable	Pain	20.4	29.6	36.3	13.7	19.6	30.4	35.8	14.2
	Other symptoms	10.1	29.7	45.1	15.1	8.3	30.8	47.3	13.7
	Psychological/spiritual	34.1	35.4	25.0	5.5	24.0	40.8	29.4	5.9
	Family/carer	32.8	31.4	28.0	7.9	20.2	35.6	36.6	7.6
Deteriorating	Pain	25.7	50.5	22.8	1.1	29.6	50.3	19.0	1.2
	Other symptoms	6.2	50.5	41.4	2.0	11.4	55.2	32.2	1.2
	Psychological/spiritual	24.3	57.0	17.6	1.1	26.6	56.8	15.9	0.7
	Family/carer	21.7	52.1	24.1	2.1	21.5	55.2	22.1	1.2
Terminal	Pain	32.8	45.4	18.6	3.2	33.7	47.5	16.4	2.4
	Other symptoms	23.8	45.9	27.3	3.0	25.2	48.5	23.5	2.8
	Psychological/spiritual	44.5	43.6	11.1	0.9	45.5	41.0	12.7	0.8
	Family/carer	21.5	41.1	34.0	3.5	15.7	48.4	33.1	2.9

5.3   Symptom Assessment Scale

The Symptom Assessment Scale (SAS) is a patient (or proxy) rated assessment tool and reports a level of distress using a numerical rating scale from 0 - no distress to 10 - worst possible distress. The SAS reports on distress from seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 34 and Table 35 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Appendix C.

Table 34   Symptom distress at phase start by phase type – inpatient setting

Phase type	Symptom	NSW Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	79.9	16.6	3.2	0.3	79.8	16.5	3.5	0.3
	Appetite problems	76.8	19.4	3.3	0.4	76.3	20.0	3.3	0.3
	Nausea	83.9	13.1	2.8	0.2	85.2	12.4	2.2	0.3
	Bowel problems	72.8	22.5	4.2	0.5	73.0	22.3	4.3	0.4
	Breathing problems	74.9	20.1	4.7	0.4	73.4	21.3	4.9	0.4
	Fatigue	53.0	37.9	8.3	0.8	51.9	36.8	10.5	0.8
	Pain	48.3	42.8	8.3	0.5	51.2	39.1	9.1	0.7
Unstable	Difficulty sleeping	63.6	24.5	9.8	2.1	60.0	24.4	12.9	2.7
	Appetite problems	59.5	31.3	8.4	0.9	57.6	29.5	11.3	1.6
	Nausea	67.7	19.2	11.3	1.8	69.0	18.9	9.9	2.2
	Bowel problems	60.7	26.4	10.6	2.3	59.6	26.1	11.8	2.5
	Breathing problems	60.2	22.4	14.0	3.4	57.7	24.3	14.1	3.9
	Fatigue	34.4	42.7	20.2	2.7	32.2	39.6	24.3	4.0
	Pain	24.8	36.6	30.2	8.4	25.9	34.7	29.7	9.7
Deteriorating	Difficulty sleeping	77.2	17.1	5.1	0.6	75.6	18.0	5.7	0.7
	Appetite problems	70.2	24.9	4.5	0.4	69.5	23.6	6.3	0.7
	Nausea	78.5	15.1	5.8	0.6	79.6	14.4	5.4	0.6
	Bowel problems	69.8	22.9	6.6	0.7	69.8	22.4	7.0	0.8
	Breathing problems	65.0	23.9	10.0	1.2	64.1	23.7	10.8	1.4
	Fatigue	41.7	42.1	14.3	1.8	41.8	38.2	18.1	1.9
	Pain	38.7	40.7	18.8	1.9	37.8	40.1	20.1	2.1
Terminal	Difficulty sleeping	91.3	6.7	1.9	0.2	91.1	6.7	2.0	0.2
	Appetite problems	93.4	5.2	1.2	0.2	92.3	5.8	1.4	0.4
	Nausea	91.3	6.7	1.8	0.2	93.0	5.3	1.5	0.2
	Bowel problems	88.4	9.3	2.0	0.4	89.4	8.4	2.0	0.3
	Breathing problems	65.8	22.0	10.3	1.8	67.0	22.0	9.3	1.7
	Fatigue	76.5	15.9	6.6	1.0	76.7	15.3	6.8	1.2
	Pain	50.4	33.9	14.0	1.6	48.6	35.2	14.7	1.5

Table 35   Symptom distress at phase start by phase type – community setting

Phase type	Symptom	NSW Services (%)				All services (%)			
		Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Difficulty sleeping	70.3	26.6	3.1	0.1	72.3	23.3	4.2	0.3
	Appetite problems	59.7	37.3	2.9	0.0	62.7	33.9	3.3	0.2
	Nausea	81.9	17.1	1.0	0.0	84.2	14.6	1.1	0.1
	Bowel problems	67.8	28.9	3.2	0.1	72.1	24.9	2.8	0.2
	Breathing problems	60.3	33.6	5.9	0.2	62.0	32.0	5.7	0.3
	Fatigue	28.2	58.5	13.0	0.3	30.3	54.1	14.8	0.7
	Pain	42.5	50.8	6.5	0.2	46.5	47.7	5.5	0.3
Unstable	Difficulty sleeping	48.0	28.3	19.8	3.9	49.3	27.6	20.3	2.8
	Appetite problems	41.2	40.4	16.2	2.2	42.1	38.0	17.6	2.3
	Nausea	62.9	17.7	15.0	4.4	60.6	20.0	16.0	3.5
	Bowel problems	52.9	26.1	17.0	4.0	52.5	26.7	17.2	3.6
	Breathing problems	51.4	26.5	17.1	5.1	50.0	28.0	17.7	4.4
	Fatigue	25.4	34.6	33.2	6.8	20.6	37.0	36.2	6.3
	Pain	20.2	26.1	37.6	16.0	18.3	33.7	34.4	13.5
Deteriorating	Difficulty sleeping	58.6	30.1	10.6	0.7	63.6	26.6	9.2	0.5
	Appetite problems	43.5	45.8	10.0	0.6	48.7	41.7	9.1	0.6
	Nausea	70.9	21.2	7.2	0.7	74.2	20.1	5.3	0.4
	Bowel problems	57.0	31.8	10.5	0.7	61.0	29.8	8.6	0.5
	Breathing problems	49.4	33.2	16.1	1.3	53.1	33.2	12.6	1.0
	Fatigue	18.3	46.0	33.5	2.2	21.9	46.6	29.6	2.0
	Pain	28.3	45.8	23.8	2.1	30.7	49.1	18.6	1.6
Terminal	Difficulty sleeping	79.3	14.6	6.2	0.0	79.0	15.4	5.1	0.5
	Appetite problems	80.0	16.9	3.0	0.2	83.5	11.5	4.3	0.6
	Nausea	88.3	9.6	2.0	0.2	84.9	10.9	3.8	0.3
	Bowel problems	74.5	21.7	3.7	0.2	76.1	19.0	4.7	0.2
	Breathing problems	57.3	30.4	10.6	1.7	63.2	25.7	9.8	1.4
	Fatigue	60.7	16.3	21.1	1.9	64.6	17.3	15.4	2.6
	Pain	39.6	38.8	18.1	3.5	37.3	41.7	19.2	1.8

## 5.4 Resource Utilisation Groups – Activities of Daily Living

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) tool consists of four items to assess the patient's level of functional dependence and give an overall picture of the level of assistance required for patient care. These four items are bed mobility, toileting, transfers and eating. The RUG-ADL items are assessed daily for inpatients, or at each visit or phone contact for patients in the community. The items are reported at admission to the service, when the phase changes and at discharge.

Table 36 summarises the RUG-ADL items at phase start for inpatient and community patients.

Table 36   The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) at phase start by setting of care

Item	RUG-ADL assessment at phase start	Inpatient				Community			
		NSW Services		All services		NSW Services		All services	
		N	%	N	%	N	%	N	%
Bed mobility	Independent or supervision only (1)	3,398	21.6	12,849	27.2	6,953	61.9	26,820	58.9
	Limited physical assistance (3)	2,649	16.9	6,910	14.6	1,677	14.9	6,152	13.5
	Other than two person physical assist (4)	2,087	13.3	5,345	11.3	796	7.1	3,805	8.4
	Two or more person physical assist (5)	7,562	48.2	22,173	46.9	1,802	16.0	8,777	19.3
Toileting	Independent or supervision only (1)	2,358	15.1	8,456	17.9	5,719	50.9	21,684	47.6
	Limited physical assistance (3)	2,884	18.4	8,491	18.0	2,408	21.4	8,913	19.6
	Other than two person physical assist (4)	2,509	16.0	6,708	14.2	1,155	10.3	5,381	11.8
	Two or more person physical assist (5)	7,896	50.5	23,564	49.9	1,945	17.3	9,573	21.0
Transfers	Independent or supervision only (1)	2,359	15.1	8,432	17.9	5,675	50.6	21,230	46.6
	Limited physical assistance (3)	2,821	18.0	8,205	17.4	2,467	22.0	9,227	20.3
	Other than two person physical assist (4)	2,416	15.5	6,440	13.6	1,110	9.9	5,232	11.5
	Two or more person physical assist (5)	8,038	51.4	24,106	51.1	1,972	17.6	9,834	21.6
Eating	Independent or supervision only (1)	5,745	36.7	19,112	40.7	7,390	66.0	28,777	63.7
	Limited physical assistance (2)	3,914	25.0	9,411	20.0	2,001	17.9	8,230	18.2
	Extensive assistance/total dependence/tube fed (3)	5,989	38.3	18,454	39.3	1,803	16.1	8,154	18.1

Figure 13   **Distribution of patients RUG-ADL Total at episode start**

Inpatient

Community
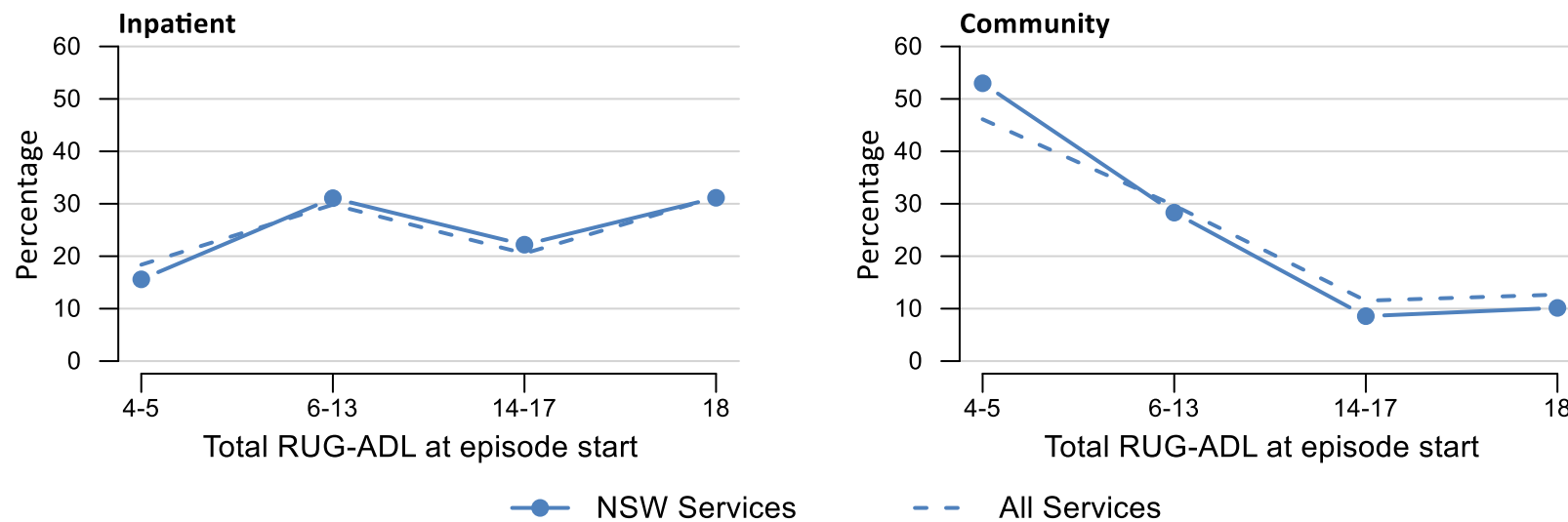
## 5.5   Australia-modified Karnofsky Performance Status

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 (deceased) and 100 (normal performance, no evidence of disease). For PCOC, patients are assessed from 10 (comatose or barely rousable) to 100. The AKPS is assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. It is recorded as part of the five PCOC assessment tools.

Table 37 shows the performance status of patients using the AKPS at phase start.

Table 37   **Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting of care**

AKPS assessment at phase start	Inpatient				Community			
	NSW Services		All services		NSW Services		All services	
	N	%	N	%	N	%	N	%
Comatose or barely rousable (10)	1,687	10.6	6,075	12.5	262	2.3	1,598	3.2
Totally bedfast and requiring extensive nursing care (20)	4,386	27.6	13,361	27.4	1,170	10.3	5,547	11.2
Almost completely bedfast (30)	2,582	16.2	7,053	14.5	882	7.8	4,379	8.9
In bed more than 50% of the time (40)	3,189	20.0	8,765	18.0	2,062	18.2	8,384	17.0
Requires considerable assistance (50)	2,107	13.2	6,271	12.9	3,170	28.0	12,112	24.5
Requires occasional assistance (60)	1,086	6.8	3,791	7.8	2,516	22.2	10,115	20.5
Cares for self (70)	269	1.7	1,010	2.1	862	7.6	4,287	8.7
Normal activity with effort (80)	62	0.4	260	0.5	172	1.5	805	1.6
Able to carry on normal activity; minor signs or symptoms (90)	19	0.1	66	0.1	s	s	171	0.3
Normal; no complaints; no evidence of disease (100)	0	0.0	15	0.0	s	s	13	0.0
Not stated/inadequately described	529	3.3	2,079	4.3	166	1.5	1,995	4.0
Total	15,916	100.0	48,746	100.0	11,314	100.0	49,406	100.0

Figure 14   **Distribution of AKPS for patients at episode start**

Inpatient

Community

NSW Services   All Services
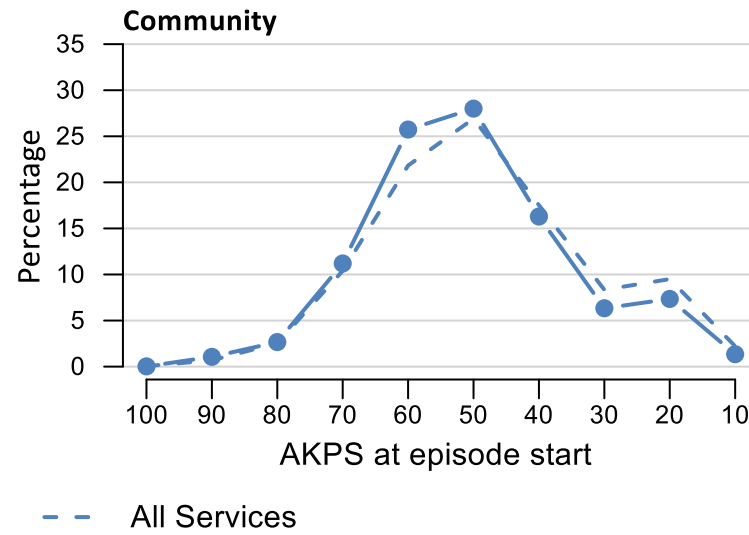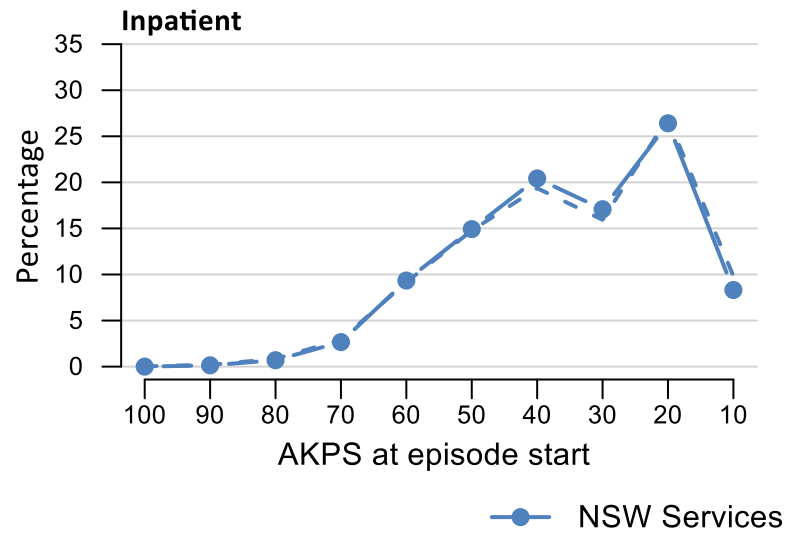
Appendices

A   Summary of data included in this report

During the reporting period, data were provided for a total of 36,772 patients who between them had 45,484 episodes of care and 98,152 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix D contains a more detailed explanation of this process). Table 38 shows the number of patients, episodes and phases included in this report – both for NSW services and all participating PCOC services nationally.

Table 38   **Summary of patients, episodes and phases by setting**

	Inpatient		Community		Total	
	NSW Services	All services	NSW Services	All services	NSW Services	All services
Patients (N)	5,413	19,406	3,982	18,863	9,095	36,772
Episodes (N)	6,133	22,945	4,576	22,539	10,709	45,484
Phases[1] (N)	15,916	48,746	11,314	49,406	27,230	98,152
Patients (%)	59.5	52.8	43.8	51.3	100.0	100.0
Episodes (%)	57.3	50.4	42.7	49.6	100.0	100.0
Phases[1] (%)	58.5	49.7	41.5	50.3	100.0	100.0
Average number of phases per episode[2]	2.5	2.1	2.4	2.1	2.5	2.1

[1] Bereavement phases are excluded from this count.

[2] Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 39 shows the number of completed episodes and phases by setting of care for each month in the current reporting period for NSW services. This table allows NSW services to identify any significant change in the number of episodes and phases during the reporting period.

Table 39   **Number of completed episodes and phases by month and setting**

Setting		Jan	Feb	Mar	Apr	May	Jun
Inpatient	Completed episodes (N)	986	957	1,056	877	1,013	938
	Completed phases (N)	2,831	2,602	2,934	2,424	2,655	2,470
Community	Completed episodes (N)	575	549	639	589	652	620
	Completed phases (N)	1,738	1,709	2,058	1,760	2,151	1,898

Table 40 shows the number of patients, episodes and phases for NSW services over time and is reported by setting of care. It allows you to identify any significant changes in volume over a three-year period and may assist in understanding changes in service delivery or model of care.

Table 40   **Number of patients, episodes and phases by setting and reporting period**

	Inpatient						Community					
	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023	Jul-Dec 2020	Jan-Jun 2021	Jul-Dec 2021	Jan-Jun 2022	Jul-Dec 2022	Jan-Jun 2023
Patients[1]	3,329	4,108	5,105	4,854	4,221	5,413	3,361	3,411	3,244	2,967	2,230	3,982
Episodes	3,789	4,587	5,765	5,393	4,741	6,133	4,220	4,231	3,923	3,462	2,553	4,576
Phases[2]	10,166	11,629	13,863	13,048	11,604	15,916	10,335	9,447	9,907	8,699	6,249	11,314
Phases per episode[3]	2.7	2.5	2.4	2.4	2.4	2.5	2.4	2.2	2.4	2.5	2.4	2.4

[1] Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

[2] Bereavement phases are excluded from this count.

[3] Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Note: The volume of data for NSW services is lower than in recent reports. See the Introduction for more information.

B   Data item completion

Table 41, Table 42, Table 43 and Table 44 report the rate of data completion. In reviewing the tables the percentage represents the number of valid records as a proportion of the number of records where the data item was relevant. For example, place of death is only required for episodes that end in death – episodes that end in discharge will not have a place of death.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

Table 41   Item completion (%) - patient level

Data item	NSW Services	All services
Date of birth	92.7	92.4
Sex	99.9	100.0
Indigenous status	98.4	96.7
Country of birth	98.4	97.7
Preferred language	99.9	99.1
Diagnosis	99.8	98.3

Table 42   Item completion (%) - episode level, by setting of care

Data item	Inpatient		Community		Total	
	NSW Services	All services	NSW Services	All services	NSW Services	All services
Date of first contact	99.8	99.9	99.9	99.4	99.8	99.7
Referral date	100.0	100.0	99.9	99.8	100.0	99.9
Referral source	99.9	99.7	99.8	99.8	99.9	99.7
Date ready for care	95.6	98.8	90.6	97.4	93.5	98.1
Mode of episode start	99.9	99.1	97.9	99.1	99.1	99.1
Accommodation at episode start	99.0	99.5	100.0	96.5	99.5	97.7
Episode end date[1]	96.9	98.8	82.5	86.2	90.7	92.6
Mode of episode end	99.5	98.2	99.7	97.7	99.6	98.0
Accommodation at episode end	97.6	98.6	99.8	97.7	98.1	98.3
Place of death	-	-	97.3	94.6	97.3	94.6

[1] Episode end date item completion may be affected by open episodes.

**Table 43**   Item completion (%) - phase level, by setting of care

Data item	Sub-Category (where applicable)	At phase start Inpatient		At phase start Community		Total		At discharge Inpatient		At discharge Community		Total	
		NSW Services	All services	NSW Services	All services	NSW Services	All services	NSW Services	All services	NSW Services	All services	NSW Services	All services
RUG-ADL	Bed mobility	98.6	97.0	99.2	92.2	98.9	94.6	65.5	70.9	33.8	51.3	49.2	60.1
	Toileting	98.3	96.9	99.2	92.2	98.7	94.5	65.5	70.9	33.8	51.3	49.2	60.1
	Transfers	98.2	96.8	99.2	92.1	98.6	94.5	65.5	70.9	33.8	51.3	49.1	60.1
	Eating	98.3	96.4	98.9	91.4	98.6	93.9	65.5	70.7	33.6	50.9	49.1	59.8
PCPSS	Pain	95.6	96.9	97.7	95.3	96.5	96.1	63.8	73.1	33.4	52.0	48.1	61.4
	Other symptoms	95.6	95.4	97.8	93.4	96.5	94.4	63.8	72.5	33.6	49.4	48.2	59.7
	Psychological/spiritual	95.4	96.3	97.2	93.9	96.1	95.1	63.7	72.3	33.3	51.1	48.0	60.6
	Family/carer	94.6	89.2	96.5	89.4	95.4	89.3	62.3	62.3	32.8	46.8	47.1	53.7
SAS	Difficulty sleeping	85.0	85.3	97.0	90.0	90.0	87.6	57.2	59.0	29.8	49.3	43.1	53.7
	Appetite problems	85.0	85.3	97.0	90.4	90.0	87.9	57.2	58.9	29.8	49.5	43.1	53.7
	Nausea	85.1	85.4	97.3	91.4	90.2	88.4	57.3	59.1	29.9	50.2	43.2	54.2
	Bowel problems	85.1	85.3	97.0	90.5	90.1	87.9	57.3	59.0	29.8	49.4	43.1	53.7
	Breathing problems	85.2	85.5	97.3	91.0	90.2	88.3	57.3	59.2	30.0	50.1	43.2	54.1
	Fatigue	85.1	85.4	97.3	91.6	90.2	88.6	57.1	59.0	30.1	50.5	43.2	54.3
	Pain	85.4	85.7	97.8	93.9	90.5	89.8	57.2	59.2	30.3	52.0	43.3	55.2
AKPS	-	96.7	95.7	98.5	96.0	97.4	95.8	65.3	70.4	37.6	53.1	51.0	60.9

Table 44   Item completion (%) - phase end, by setting of care

Data item	Inpatient		Community		Total	
	NSW Services	All services	NSW Services	All services	NSW Services	All services
Phase End Reason	99.0	99.6	99.3	98.9	99.1	99.3

C   Profile of patient symptoms and problems

Figure 15   Profile of symptoms and problems by phase type for NSW Services – inpatient setting
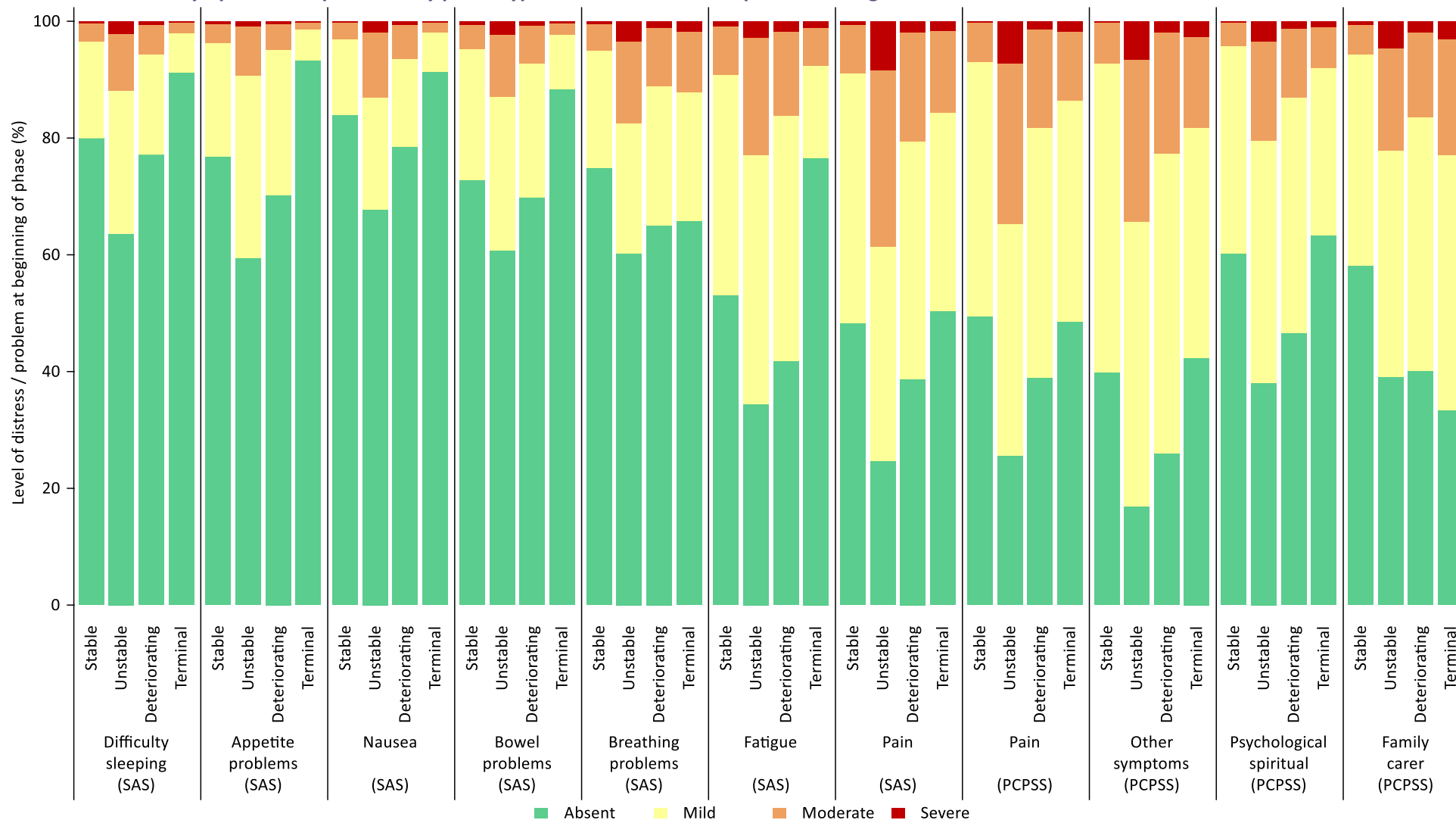
Figure 16 **Profile of symptoms and problems by phase type for NSW Services – community setting**
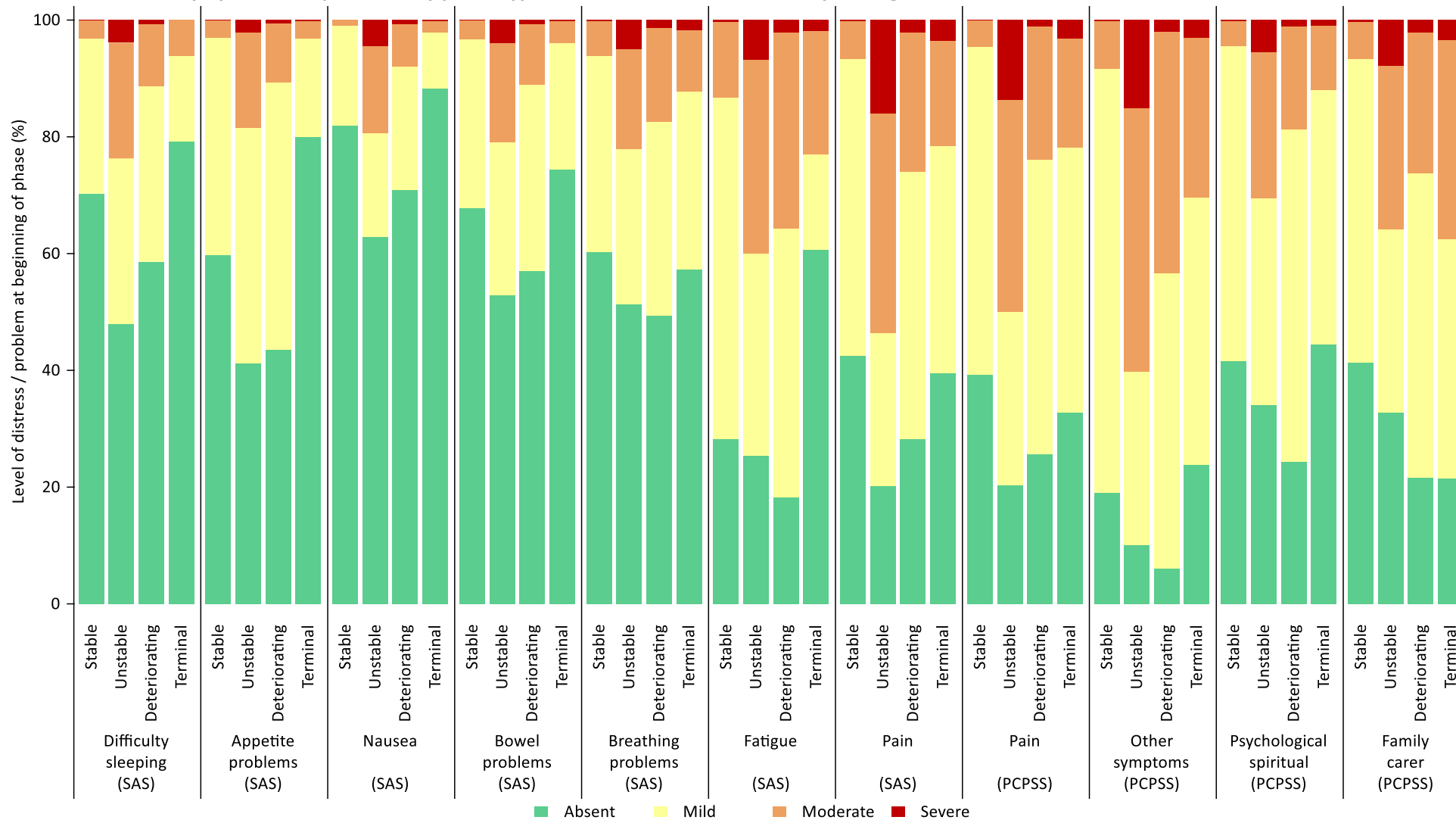
D   Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that <u>end</u> within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 17 below displays four examples to help visualize this process.

Figure 17   Diagram of the PCOC data scoping method
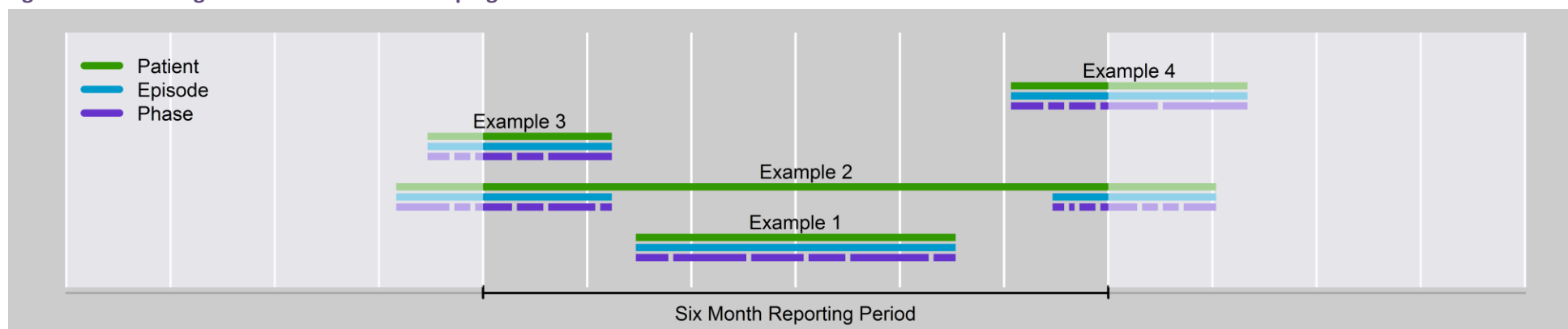
In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

In Example 3, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

E   Interpreting benchmark profile graphs

The national profile graphs present NSW Services in comparison to all other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. NSW Services inpatient service are highlighted as a black dot on the graph. NSW Services community service are highlighted as black triangle on the graph.

Inpatient service results are represented by a black dot. If you do not have an inpatient service or you have less than 10 observations in this measure, then this dot will not appear.

Community service results are represented by a black triangle. If you do not have a community service or you have less than 10 observations in this measure, then this triangle will not appear.

The red line indicates the benchmark for this outcome measure

The blue region indicates the national profile. This contains all services across the country that have contributed to this benchmark ordered from the highest score to the lowest score. The highest score is on the left side of the graph and the lowest score is on the right side of the graph

Anticipatory care - Pain (PCPSS)
% absent to mild at phase end, when absent to mild at phase start

Services ordered from highest to lowest score

91.9%

89%

Percentage of phases

F   Palliative Care Phase definitions

Phase type	Start	End
Stable	- Patient problems and symptoms are adequately controlled by established plan of care **and** - Further interventions to maintain symptom control and quality of life have been planned **and** - Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required **because** - Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** - Patient experiences a rapid increase in the severity of a current problem; **and/or** - Family/carers circumstances change suddenly impacting on patient care.	- The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and/or** - Death is likely within days (i.e. patient is now terminal).
Deteriorating	The care plan is addressing anticipated needs but requires periodic review **because** - Patients overall functional status is declining **and/or** - Patient experiences a gradual worsening of existing problem **and/or** - Patient experiences a new but anticipated problem **and/or** - Family/carers experience gradual worsening distress that impacts on the patient care.	- Patient condition plateaus (i.e. patient is now stable) **or** - An urgent change in the care plan or emergency treatment **and/or** - Family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** - Death is likely within days (i.e. patient is now terminal).
Terminal	Death is likely within days.	- Patient dies **or** - Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).

Acknowledgements